Arthritis, Aches and Pains, and Arthritis Services:

Experiences from within an Urban First Nations Community

by

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ABSTRACT

This dissertation explored the experiences of health and healthcare reported by members of an urban First Nations community who had arthritis and the ways in which arthritis health services were aligned (or not aligned) with these experiences. Using a community-based, participatory design, grounded in decolonizing methodologies and ethnographic methods, this study had two research fields that related to the research questions. Study activities in one research field included intensive immersion in a First Nations community over a period of three years, and interviews with 24 community members. In the second field, which included three arthritis services settings, study activities involved approximately 100 hours of immersion and interviews with 30 healthcare professionals. The analysis of community-based data revealed that experiences of ongoing arthritis/pain and social suffering were inextricably linked to and underpinned by the social and historical context of life in the community. Most, but not all, community participants were reluctant users of health services, largely related to prior negative experiences utilizing health services. The organization and delivery of arthritis health services, shaped by dominant healthcare discourses, were not well aligned with the experiences of First Nations peoples with arthritis; rationing and biomedical discourses limited the ability of the system to be responsive to social contexts, and culturalist and self-management discourses served to deflect healthcare professionals’ attention away from the role that social and material life conditions played in shaping the experiences of First Nations individuals living with arthritis. Amongst arthritis health services leaders and professionals there was a sincere desire to provide effective, quality care to all people with arthritis. Creating more opportunities for social/critical knowledge to be present in health services settings could go a long way towards improving the alignment of arthritis services with arthritis experiences of First Nations peoples.

PREFACE

Ethics approval for this study was received from the University of British Columbia, Behavioural Research Ethics Board. This study was originally approved in June, 2006; the last annual renewal was received in October, 2010 (H06-03901-A006).

Permission to interview healthcare professionals was granted through the Vancouver Health Authority Research Institute, Approval number V07-0168 (2007-2009).

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LIST OF ACRONYMS

AE Aboriginal epistemology

AFN Assembly of First Nations

ASMP Arthritis self-management program

CAC Community advisory committee

CBPR Community-based participatory research

CCM Chronic care model

CDSMP Chronic diseases self-management program

CHSRF Canadian Health Services Research Foundation

CHSPR Centre for Health Services Policy Research

CIHR Canadian Institutes of Health Research

CRA Community-based research assistant

DMARDS Disease-modifying anti-rheumatic drugs

FM Fibromyalgia

FNC First Nations Centre

FNIH First Nations and Inuit Health

HCP Healthcare professional

IPV Intimate partner violence

KT Knowledge translation

NIHB Non-insured health benefits

OA Osteoarthritis

OASIS OsteoArthritis Services Integration System

OCAP Ownership, control, access, possession

OT Occupational therapist

PCF Post-colonial feminism

PHO Provincial Health Officer

PT Physiotherapist

RA Rheumatoid arthritis

RHS National Regional Longitudinal Health Survey

USA United States of America

VCH Vancouver Coastal Health

WHO World Health Organization

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My most profound thanks go out to the community members who engaged with me for this research. In particular, my community partner enabled the research. Without her there would be nothing to write. In addition, the members of the Community Advisory Committee had a critical role. They were a force to be reckoned with and I feel so fortunate to have had them on my side. Further, the community research assistants each contributed something unique and valuable to the research. The mark left by them on this work and on myself reflects a gift for which I will be eternally grateful. Finally, the men and women who shared their stories represent the bricks and mortar of this dissertation; their generosity will be long remembered.

Similarly, many healthcare professionals were vital to this dissertation. My healthcare partner and his boss have been an ongoing source of motivation for me. Their enthusiasm for the project, and for improving arthritis care for Aboriginal peoples, was evident from our first discussions, and it remains today, years later.

The scaffolding for this work was constructed largely through the guidance of Dr. Joan Anderson. Joan took me on as an undisciplined student and patiently shaped who I am today. She once told me that her own doctoral supervisor had been one of the most influential people in her life; as my original supervisor, I cannot say loudly enough, how grateful I am that she applied her considerable wisdom towards the project of my (and my dissertation's) becoming.

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The life of this dissertation has been a reflection of my own journey. I have had so many teachers as I travelled my path. In presenting this dissertation I hope to honour the many teachers and supporters that have created the outcome that is both me and my dissertation. It has been a remarkable experience.

CHAPTER ONE: INTRODUCTION

Background to the Study

The burden of arthritis[1] is high in Canadians who identify as Aboriginal[2]. Arthritis is the leading cause of disability and chronic pain in Aboriginal populations (First Nations Centre [FNC], 2005), and a leading cause of poor quality of life (Young et al., 1998). Arthritis can be understood as a collection of musculoskeletal conditions involving inflammation of the joints (Reading, n.d.). It is typically identified as the most common chronic illness in Aboriginal adults; prevalence rates (age adjusted) of at least 25% are often reported, compared to 19.1% in the general Canadian population (FNC). Since arthritis is more prevalent in older populations, the burden of arthritis in Aboriginal populations can be expected to grow as the Aboriginal population, as a whole, ages.

Despite the significant prevalence and impact of arthritis on Aboriginal populations in Canada, arthritis remains relatively unstudied in both Aboriginal and non-Aboriginal populations (Barnabe, Elias, Bartlett, Roos, & Peschken, 2008). A review of arthritis-related publications for the period of 1991–1996 (Glazier, Fry, & Badley, 2001) revealed that although arthritis and related conditions are “leading contributors to health professional consultations, total health costs, chronic ill health, and disability" (p. 706), they ranked only ninth among 12 major disease categories in number of publications. Similarly, the Arthritis Society (Arthritis Society of Canada, 2004) notes that arthritis accounts for 10% of the economic burden of illness in Canada but only one percent of the health science research budget. More knowledge of arthritis, and peoples' experiences of living with arthritis, needs to be generated to address the growing burden of this illness.

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[1] I use the phrase *burden of arthritis* in this dissertation to refer to the sum of the effects of arthritis on communities, including the implications of rates of prevalence in terms of morbidity and mortality (i.e. the effects of having large numbers of people with activity limitations, chronic pain, and/or high needs for health services).

[2] I use the term *Aboriginal* in keeping with the Royal Commission on Aboriginal Peoples (1993) that identifies three recognized and distinct groups of Aboriginal peoples in Canada: First Nations peoples, Métis peoples, and Inuit. These categories replace the terms Indian and Eskimo that were widely used in the past (an exception to the use of these newer terms is the case of the Canadian Department of Aboriginal Affairs and Northern Development; this department continues to use the term Indian). In this paper the term Aboriginal refers to Aboriginal peoples as a group. I use the term First Nations when referring to specific First Nations groups. While I have used the term Aboriginal to reflect the accepted nomenclature at the time this research was conducted, I am aware that in a growing number of contexts the term indigenous is preferred or the naming of all three groups, First Nations, Inuit and Métis.

A notable exception to the relative dearth of research on arthritis in Aboriginal populations is the body of research on the genetic underpinnings of arthritis, particularly rheumatoid arthritis (RA)[3]. The genetic underpinnings of arthritis in Aboriginal populations has been a topic of great interest to researchers since the 1960s (see Enzer et al., 2002; Gofton, Robinson, & Price, 1964), and the finding of genetic markers[4] for RA in large segments of some Aboriginal populations has fueled this focus for research over time. However, even though genetic markers for RA are common in some Aboriginal populations, not everyone with the markers has been found to subsequently develop RA. Further, some people without the markers go on to develop RA. Hence, genetic markers alone cannot provide a platform for understanding arthritis in Aboriginal populations or for identifying who is at risk for arthritis. It is now widely acknowledged that "genes alone determine nothing in connection with the majority of diseases"

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[3] Although most commonly studied, RA is not the most prevalent form of arthritis. In all populations, osteoarthritis (OA) is more common by a margin of about 10:1. Unlike RA, a genetic underpinning of OA has not been the focus of research. OA is more commonly linked to wear and tear of the joints that has occurred over time. RA and OA are the two most commonly discussed arthritic conditions in health discourses.

[4] The term genetic marker refers to particular gene variations that can be found in DNA (Lui & Muse, 2005). Genes have been widely thought to be predetermined units of hereditary information (Lock, Cox, & d'Agincourt-Canning, 2006) and because arthritis (RA) was thought to be a hereditary disease, the search for genes that determined arthritis was a valued scientific endeavor. In recent years, genes have been found to have a much more complex relationship with disease as their expression is shaped by a variety of contextual factors (Lock et al.).

(Lock, Freeman, Chitibeck, Beveridge, & Padolsky, 2007, p. 257). Hence, an understanding of the problem of arthritis in Aboriginal populations requires a broader research agenda beyond the genetic basis of RA.

Research about arthritis (broadly defined) in Aboriginal populations, that explores how historical and social processes mediate peoples' health and healthcare experiences, is needed. For instance, some researchers have shown how involuntary cultural change and stress have shaped the health status of Aboriginal populations (i.e. Bartlett, 2003); others have shown how access to (effective) healthcare has been problematic for many Aboriginal individuals (e.g. Adelson, 2005; Browne, 2005, 2007; Browne et al., 2011; O'Neil, 1989). These bodies of research help to explain why Aboriginal peoples[5] experience a higher burden of illness in comparison to the general Canadian population[6], not just in the case of arthritis but in almost every illness category. Because this differential burden has been clearly linked with past histories of colonization in

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[5] I have deliberately used the plural of the term *people* in this dissertation in my references to whole Aboriginal or First Nations populations. For instance, I use the phrase *First Nations peoples* when I am referring to all people who identify as First Nations. By using the plural of the term I signify my awareness that Aboriginal populations are comprised of many diverse and unique sub-populations, and that collapsing all sub-populations into one larger category has the potential to erase this diversity.

[6] In this dissertation, I rely on statistical information that is available to describe the health of Aboriginal peoples in relation to other Canadians. The common practice, shaped by data that are available, is to compare health indicators of Aboriginal populations with those of the *general Canadian population* (meaning the Canadian population as a whole). While this approach is helpful in that it draws attention to the particular population of Aboriginal peoples being discussed, it suggests a homogeneity within the Canadian population (and within the Aboriginal population) that is artificially construed. Such an approach obscures how intersections of gender, race, class, age, and other social determinants of health shape health outcomes. For instance, prevalence rates of arthritis in older Aboriginal women who experience a high degree of social suffering may be similar to rates of arthritis in older, first generation immigrants who experience social suffering to a similar degree. While I am mindful of these limitations of population level data, I draw on population level comparisons in part because these are the data that are available and in part to foreshadow population-based approaches that may be warranted.

Canada, and ongoing social and political processes, it is aptly characterized as a health inequity[7] in Aboriginal populations (Adelson, 2005).

The Social and Historical Context of Aboriginal Peoples' Health and Healthcare

The differences in health status between Aboriginal populations and the general Canadian population reflect the "present day health effects of decades of inequity" experienced by Aboriginal peoples (Adelson, 2005, p. S45). The history of colonization in Canada, and the related ongoing policies, have led to a situation where many individuals who are Aboriginal, and many Aboriginal communities in Canada, experience life contexts that affect health status (Garman & Doull, 2009). For example, colonial policies of paternalism, assimilation, and discrimination resulted in acts such as outlawing certain cultural practices, separating children from families for the purposes of residential schooling, allocating reserve[8] lands in lieu of individual land title rights, and the bias against people of Aboriginal heritage in the job market (Waldram, Herring, & Young, 2006). These historical conditions contributed to lived experiences of Aboriginal peoples, often including distress and duress (Rock, 2003), that played out in the form of lack of employment opportunities in First Nations communities, economic marginalization and high rates of poverty and related social issues (Bartlett, 2003; Brave Heart,

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[7] I use the term *inequity* to signal a difference in health status that is avoidable and unjust (Carter-Pokras & Baquet, 2002). This contrasts the term inequity with the term *inequality*, which signals a difference in health status that is not seen as avoidable or necessarily unjust (such as higher rates of cancer in older people than in younger people). The term *disparity* has sometimes, but not always, been used interchangeably with the term inequity. Because of the lack of clarity in the definition of this later term, in this dissertation, I restrict my use of the word disparity to direct quotations, which tend to align the terms inequity and disparity.

[8] In Canada, lands allocated by the federal government for the sole use of specified First Nations are called reserves. This is in contrast to lands allocated in the United States that are called reservations.

2003; Christian & Spittal, 2008). Aptly described as *social suffering*[9] (Kleinman, Das, & Lock, 1996), these lived experiences continue to be felt today as many Aboriginal individuals and communities experience systemic inequities including inadequate housing, employment, income sources, educational opportunities, and environmental conditions. People who experience such hardships and stressors are at higher risk of developing illnesses, particularly chronic conditions like arthritis (World Health Organization [WHO], n.d.). The health status of Aboriginal peoples is therefore embedded in the historical context and the associated “structures of inequity and domination” that persist today (Furniss, 1999, p. 15). Hence, systemic social structures perpetuate social and material inequity for Aboriginal populations; these forms of inequities are also understood as structural violence[10] (Farmer, Nizeye, Stulac, & Keshavjee, 2006), and potently shape the health of Aboriginal peoples.

Historically, the health system was a powerful tool in the project of colonization (Kelm, 1998) and today it continues to reproduce the power dynamics of broader society (O’Neil, 1989). Researchers continue to document that healthcare professionals often unwittingly draw on stereotypes of Aboriginal peoples as they provide care and, in doing so, reinscribe social dynamics in healthcare that unfairly disadvantage Aboriginal peoples (Browne, 2005, 2007; O’Neil). Healthcare for Aboriginal peoples unfolds against a backdrop of internal colonial relations[11] (Browne, 2005, 2007). In addition, health programs and services for Aboriginal populations tend to be designed largely without input from Aboriginal peoples (e.g. Fontaine, 2005). Aboriginal leaders argue that programs designed without taking into account the perspectives of Aboriginal peoples are destined to be ineffective at improving health (Fontaine). Thus, healthcare policies and structures, which shape healthcare services and practices, create barriers to effective healthcare, exacerbating inequities in health and healthcare.

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[9] Kleinman, Das, & Lock (1996) describe social suffering as the assemblage of social problems that are experienced as a result of the injuries inflicted by social forces.

[10] Structural violence refers to the harm that social structures, like inadequate housing, can inflict on humans (Farmer et al., 2006).

[11] Internal colonialism refers to “Forth World” situations, where a minority indigenous population is segregated within a nation-state that holds power and privilege as a colonizing majority. The majority population consciously and unconsciously subordinates the original inhabitants of the land (O’Neil, 1989).

Today, in the midst of changing power dynamics, attributable in part to Aboriginal peoples' continued resistance and resilience in the face of oppressive practices and structures (Furniss, 1999; Kelm, 1998), healthcare policy leaders are striving to improve the health system's response to persistent health and healthcare inequities. Efforts to improve the system's responsiveness are reflected in federal and provincial policy mandates to reduce health inequities (Health Canada, n.d.) and improve "delivery of, and access to, culturally appropriate health services tailored to meet the needs of First Nations communities…" (British Columbia [B.C.] Ministry of Health Services, 2010). These goals signal healthcare discourses that seek social justice for Aboriginal peoples in Canada.

However, the ways that other intersecting discourses have been taken up in healthcare settings shape the outcomes of these social justice initiatives. For instance, the widespread discourse on healthcare efficiency in Canada, throughout North America and beyond, has fueled a drive to contain healthcare costs in the short term, with limited acknowledgement of longer term outcomes (e.g. Matsuda, 2008). While arguments for an efficient health system are compelling, efficient healthcare that is not also effective at meeting peoples' healthcare needs (and thus potentially reducing healthcare inequities) is clearly problematic (Tuohy, 2002). Another powerful discourse in healthcare is the chronic illness self-management discourse, which tends to obscure the influence of the social determinants of health and emphasize individual responsibility[12] for health (Raphael, Curry-Stevens, & Bryant, 2008). Hence, the health system's responses to health and healthcare inequities affecting Aboriginal peoples are unfolding within a complex milieu of social forces.

Arthritis services in B.C. are unfolding within this complex milieu. A plethora of arthritis-specific services are available, including secondary care through specialists (e.g. rheumatologists and orthopedic surgeons) and tertiary care through specialist referral to provincial arthritis programs. However, these services may not be well-accessed by First Nations peoples living in British Columbia. For instance, Canadian literature suggests that Aboriginal peoples, especially urban peoples, access fewer specialists (including arthritis specialists) than the general Canadian population, even though their morbidity is greater (Barnabe et al., 2008; Martens, Sanderson, & Jebamani, 2005a). This reality is particularly troubling since statistics show that increasing numbers of individuals who identify as Aboriginal are moving to urban locations (Browne, McDonald, & Elliot, 2009; Newhouse, 2004). In addition, the populations on urban reserves are increasing (Browne, McDonald et al.). More than 50% of the Canadian Aboriginal population now lives in urban areas (Statistics Canada, 2008). Hence, the effectiveness of the system in meeting the needs of First Nations peoples with arthritis, particularly those living in urban areas, is particularly salient to study.

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[12] The argument I am making here is not that individual responsibility is an inappropriate concept. Indeed, a central argument of post-colonial literature is that individuals are competent agents who do and can take responsibility and make choices but choices are bound by structural constraints (e.g. Reimer-Kirkham & Anderson, 2002). The problematic lies in way that the concept of individual responsibility has been taken up. When structural constraints and difficult life contexts are ignored, patients are blamed for their poor health under the guise of individual responsibility; patients with poor health are assumed to lack personal responsibility for their health. As such, discourses of individual responsibility, in the absence of concurrent attention to social determinants of health, unfairly position patients as being solely responsible for their poor health.

The Historical and Current Context of Research Involving Aboriginal Peoples

Just as the health system has historically been implicated in perpetuating colonial relations, so has academic research. In fact, Tuhiwai Smith (1999), a Maori scholar, argues that “scientific research is implicated in the worst excesses of colonialism” (p. 1) as researchers objectified Aboriginal peoples and applied their own interpretive lens, tainted with the ideologies of colonialism, to the data they collected. As a result, the knowledge that was produced was typically exploitative and failed to provide understandings that were of benefit to Aboriginal peoples. Aboriginal peoples’ lack of power in determining what was perceived as truth ensured that knowledge produced served to maintain the power imbalance between Aboriginal peoples and members of the dominant society.

In Canada today, health research guidelines published by the Canadian Institute for Health Research (CIHR), Canada’s national health research funding body, mandate research protocols that include power sharing with Aboriginal peoples when they are the subject of research (CIHR, 2008). While these protocols help protect against exploitative research, Aboriginal scholars are calling for research protocols to go further to ensure that research concerning Aboriginal peoples contributes to decolonization. Such research explicitly foregrounds Aboriginal perspectives and locates the locus of the problem within social or structural issues as opposed to solely within individual or community factors (Tuhiwai Smith, 1999). Decolonizing research carries the potential of producing knowledge that can address the social and health inequities experienced by Aboriginal peoples in Canada.

Although research with a decolonizing intent has begun to appear in the health sciences, such research on the topic of arthritis in Aboriginal peoples could not be found. Available research on the topic largely continues to position arthritis as a purely biomedical phenomenon (as opposed to, for example, a bio-social phenomenon). The research reported in this dissertation aimed to address this gap by exploring the experiences of arthritis within an urban First Nations community and the arthritis services available to community members. Conducted in partnership with a First Nations community, this research contributes to a more comprehensive understanding of First Nations peoples' experiences of arthritis. The hope is that this understanding will facilitate the development of health policy and practices that can address this important health issue.

Central Problem

Arthritis is the leading cause of disability and chronic pain and is therefore a significant health problem for First Nations peoples in Canada. However, little is known about how arthritis is experienced and how arthritis services are organized to address peoples' needs. Although specific health services have been developed to meet the needs of people with arthritis, these services have not been examined in relation to First Nations peoples' experiences of living with arthritis. Both experiences of living with arthritis and arthritis healthcare services are influenced by complex social, historical, and political factors. The ways in which these contexts shape First Nations peoples' experiences of arthritis and the design and delivery of arthritis health services requires further study.

Purpose

The purpose of this dissertation is to employ decolonizing methodologies to explore: 1) how arthritis is experienced by First Nations peoples living in an urban reserve community in B.C., and 2) the organization and delivery of arthritis services and their alignment with the health and healthcare experiences of First Nations community members.

The overall goal of the dissertation is to contribute to the knowledge that will enable the system to design and develop health services that better meet the needs of people who identify as First Nations and who have arthritis. To plan effective, responsive services for First Nations peoples with arthritis, a clearer understanding of the health and healthcare experiences of First Nations peoples living with arthritis is needed. Learning from the perspectives of First Nations peoples with arthritis is critical to the design and development of appropriate, quality health services.

The Research Questions

This study was guided by the following research questions:

1) What are the health and healthcare experiences of First Nations community members with arthritis who reside in an urban reserve community in B.C.?
2) What shapes their utilization of arthritis health services?
3) How does the current organization and delivery of arthritis health services shape the ability of services to be aligned with the experiences of First Nations community members living with arthritis?
4) What recommendations for arthritis health services can be made?

To address these questions, a community-based, participatory research project, which used ethnographic methods, was designed and implemented. The research questions directed me to two research fields. In the first field, which was an urban First Nations reserve community, I explored the health and healthcare experiences of community members with arthritis. To examine the organization and delivery of arthritis health services, the second field included fieldwork in a number of institutions providing arthritis services in the adjacent city, including interviews with healthcare professionals and observations within these settings.

Organization of the Thesis

The present chapter has provided an introduction to the research topic including the background to the problem addressed by the research and the specific research questions. The goal of this chapter was to highlight a consistent theme of this dissertation: historical, social, and structural forces intersect to organize everyday experiences of First Nations peoples with arthritis and the ways in which arthritis health services are designed and delivered.

Chapter Two of this dissertation provides a review of relevant literature focused on four topic areas. The first situates the issue of arthritis within the wider context of health inequities in Aboriginal populations, and the social and historical context of health and illness. The second topic area provides a review of chronic illness and arthritis among Aboriginal populations. The third topic area situates arthritis health services within the context of a health system that is influenced by ideologies and discourses. I focus specifically on the literature that discusses the system's response to chronic illnesses, including arthritis and chronic pain. In the fourth topic area, I discuss the literature that sheds light on the ways that Aboriginal peoples have experienced the health system and healthcare services in Canada. This review of the literature reveals the gaps in knowledge that this study aims to address.

Chapter Three describes the research methodologies and methods used in this work. I delineate my interpretation and use of decolonizing methodologies, as well as the theoretical perspectives that informed the methodology. A world view of *Two-eyed seeing* was used as an interpretive lens. Two-eyed seeing, as discussed by Mi'kmaq elder Albert Marshall, advocates for improved vision (understanding) through seeing *traditional* and *western* knowledge as equal and complimentary sources for advancing humanity's shared goals (http://www.turtleisland.org/culture/twoeyed.htm). In this study, Two-eyed seeing was informed by Aboriginal epistemology and post-colonial feminism. Although these two theoretical perspectives flow from distinct ontological and epistemological positions, they are complementary and together provided a comprehensive perspective from which to understand arthritis inequities. Two-eyed seeing was enabled because community members agreed to be partners on a journey to understand arthritis in their community and the arthritis health services available.

Chapter Four is a preamble to the findings. This chapter links the research questions and methodology with the three findings chapters.

Chapter Five, entitled “Why do I have so much pain?” is the first of the findings chapters. This chapter describes First Nations participants’ experiences of arthritis, which was reconceptualized as *aches and pains*, and their understandings of these experiences. Stories told by participants about their experiences reflect the contexts of their lives, many of which were linked to conditions of social suffering.

Chapter Six, titled “I’ve just learned how to deal with it,” describes how participants responded to their aches, pains, and mobility restrictions, including their healthcare experiences. The stories that participants told reflected a community norm to *suffer in silence*. Stories also portrayed the resources used to promote health and healing, including family, traditional medicines, and the health system.

Chapter Seven is the final findings chapter. It is devoted to the data that explores the organization and delivery of arthritis health services. The findings in this chapter show that healthcare professional participants desired to do good work with First Nations patients; however, their work was constrained by healthcare structures and discourses that shaped healthcare practices and policies. While many healthcare professionals and administrators pushed for better services, dominant healthcare discourses (e.g. biomedical and efficiency discourses) and the corresponding structures that have been set up intersected to limit the effectiveness of initiatives in arthritis care for Aboriginal peoples in British Columbia.

Chapter Eight provides an overview of the study, as well as the implications and recommendations that arise from the analysis. The major lesson learned is how embedded experiences of arthritis are in the social/historical and structural contexts of people's lives. Pain experiences could not be disentangled from the realities of participants' social experiences. Participants' bodies told the histories of their lives, histories that were often marked by significant and ongoing hardships, traumas and suffering. Similarly, social and structural contexts are powerfully active in health services design and delivery, and yet they are not always acknowledged as such. Inequities in arthritis experienced by Aboriginal populations can begin to be addressed with some changes to health and social policy, to arthritis services, and to arthritis research; these ideas for change are discussed in the implications and recommendation sections of this final chapter.

CHAPTER TWO: REVIEW OF THE LITERATURE

The purpose of this chapter is to situate this study within the broader literature on the health of Aboriginal peoples in Canada, and the organization and delivery of healthcare. This chapter reviews literature from four main areas: (a) The social and historical context of Aboriginal peoples' health, (b) chronic illnesses and arthritis in Aboriginal populations, (c) the Canadian health system with a focus on chronic illness management and the management of arthritis (including chronic pain management), and (d) Aboriginal peoples' encounters with the health system. This review provides both a broad and focused analysis of the literature that sheds light on the problem of arthritis and arthritis care in Aboriginal populations.

A systematic, comprehensive literature search provided the initial material for this review. The material was updated over the course of the project. Data bases, including Medline, Cumulative Index to Nursing and Allied Health Literature, Cochrane Database of Systematic Reviews, Embase, PsychINFO, and Sociological Abstracts, were searched using key words such as chronic pain, chronic disease, chronic illness, arthritis, Aboriginal, North American continental ancestry, American or Canadian Indian, indigenous, First Nations, health system, access, barriers, and Canada. In addition, specific literature was obtained through focused searches using Google Scholar, searches of the Health Canada website and other websites (including non-governmental organizations like the National Aboriginal Health Organization), and a hand search of key journals, for example, the Journal of the Canadian Medical Association, The Canadian Journal of Public Health, The Journal of Rheumatology, and The Journal of Aboriginal Health. Finally, a portion of the literature reviewed was obtained via *snowball* effect, that is, literature for retrieval was identified by reviewing reference lists of key articles.

The Social and Historical Context of Aboriginal Peoples' Health

It has been well-established that the historical experiences of Aboriginal peoples in Canada have influenced their health status at the population level (Adelson, 2005; British Columbia [B.C.] Provincial Health Officer [PHO], 2009). The long history of marginalization, systematic racism, and discrimination endured by Aboriginal peoples in Canada, as part of colonial laws and practices that unfolded over the past century, has created persistent social conditions that foster poor health. For instance, the segregation of First Nations peoples onto reserve lands has led to food insecurity in many cases as they are disconnected from their traditional hunting and food gathering territories (Richmond, Elliot, Matthews, & Elliot, 2005); inadequate services to those living on reserves has led to inadequate and overcrowded housing and unsafe water systems on many reserves (Adelson); and, economic marginalization via discrimination in the workforce has led to reliance on social assistance and poverty for some Aboriginal peoples (Lutz, 2008). It is now widely recognized that the social conditions in which one grows and lives "reflect some of the most powerful influences on health in the modern world" (WHO, 1998, p. 8). According to Health Canada officials, "there is overwhelmingly consistent findings in the research that confirms colonization contributed significantly to the imbalance of social determinants of health in First Nations evident today" (Garman & Doull, 2009, p. 2).

In addition to underlying material disadvantage, colonial politics have disadvantaged Aboriginal peoples on psychological, emotional, and spiritual levels. For example, colonial policies of assimilation attempted to obliterate First Nations culture through policies that outlawed certain cultural practices and legislated residential schooling for children (Bartlett, 2003; DeGagne, 2007). For many First Nations peoples, subsequent life experiences fostered intrapersonal and interpersonal challenges such as a troubled sense of personal identity, attachment and parenting difficulties, depression, anger, substance abuse/addiction, and violence (Kirmayer, Simpson, & Cargo, 2003). These outcomes, which have been passed on intergenerationally (Brave Heart, 2003), contribute to the unequal achievement of First Nations peoples, as compared to the general population, in the areas of employment, income, and education (Frohlich, Ross, & Richmond, 2006). In B.C., statistics show that rates for Aboriginal peoples in these areas are two to three times worse than for the general population (B.C. PHO, 2009). As noted by Frohlich and colleagues, statistics such as these “provide evidence of a distinct social *chasm* between Aboriginal and non-Aboriginal Canadians” (p. 135) leaving many Aboriginal peoples at a disadvantage in terms of acquiring the goods and resources that enable health.

Despite the fact that assimilation is no longer an official governmental policy, current policies that limit the self-determination of First Nations peoples are argued by many Aboriginal scholars to be a continued source of disadvantage that perpetuates poor health and social outcomes (e.g. Alfred, 2009; Ladner, 2009). These poor outcomes document a classic example of social suffering, or the “assemblage of human problems that have their origins and consequences in the devastating injuries that social force inflicts on human experience” (Kleinman et al., 1996, p. XI). At the root of this example of social suffering, as in many others, is structural violence, or “social arrangements that put individuals and populations in harm’s way” (Farmer et al., 2006, p. 1686). Adelson (2005) notes that the current health status of Aboriginal peoples in Canada reflects the “embodiment of inequity” (p. S45).

Today, Canadians who identify themselves as Aboriginal experience a disproportionate burden of ill health and suffering when compared to the general Canadian population (Adelson, 2005; B.C. PHO, 2009). On almost every health indicator imaginable, Aboriginal Canadians fare worse than their non-Aboriginal counterparts. This is true for the most basic of health indicators, life expectancy, where Aboriginal women in B.C. are expected to live to the age of 77 years and Aboriginal men to the age of 73 years, as compared to the general British Columbian population of women who are expected to live to 83.1 years and men to 78.4 years (B.C. PHO). It is also true for most health outcomes. For example, Aboriginal adults in Canada have a rate of disability of 31% compared to a Canadian national rate of 15% (FNC, 2004). Although the health gap has decreased in some areas over the past decade, in other areas, for example chronic illness, the gap continues to grow (B.C. PHO).

Chronic Illness and the Burden of Arthritis in Aboriginal Populations

Chronic illness[13] is recognized as a critical concern for all people, including Aboriginal peoples, as rates of chronic illness continue to grow (WHO, 2008). In the National Regional Health Survey (RHS) of 2002/3, 53.7% of First Nations adults living on reserve reported at least one chronic health condition (FNC, 2005). Chronic illness has been globally recognized as one of the premier challenges for people, governments, and healthcare systems because it is widespread, carries a significant toll in terms of individual wellness and economic burden, and health systems are generally ill-equipped to manage it (Yach, Hawkes, Gould, & Hofman, 2004). Populations that are disadvantaged related to the social determinants of health, like Aboriginal peoples, experience higher rates of chronic illness (WHO).

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[13] Chronic illness refers to an ever-expanding category of health problems. While some early analyses reserved the term for health conditions that were non-fatal but incurred disability, more recent definitions have included potentially life-threatening conditions, such as cancer and HIV/AIDS, since many who suffer from these conditions live for lengthy periods with ongoing sequelae. For the purposes of this project, I define chronic illness in accordance with the Canadian Community Health Survey (e.g. cycle 1.1, 2001), which defines a chronic condition as a condition that lasts at least six months and that has been diagnosed by a health professional. This definition leaves out the common qualifier that chronic illness represents illness for which there is no known cure or predictable resolution (e.g. used by Watt, Browne, Gafni, Roberts, & Bryne, 1999).

Arthritis is often identified as the most common chronic illness in Aboriginal populations (e.g. FNC, 2005). While the chronic condition of diabetes is often profiled as a significant chronic illness in Aboriginal populations, arthritis, which has not received the same degree of attention, is usually found to be more prevalent (e.g. FNC; Reading, n.d.). In Canada, 25.3% of First Nations adults (age 18+) living on reserve report arthritis, as compared to 19% (age 20+) in the general Canadian population (FNC). Although the overall prevalence rate of arthritis in Canada has been stable over the past several years (e.g. prevalence rate in Canadians age 12 and over was 16.4% in 2004 and 15.2% in 2009; Statistics Canada, 2010), in Aboriginal populations the prevalence rate seems to be increasing. For example, the Aboriginal Peoples Survey (Aboriginal peoples living off reserve) reported an arthritis prevalence rate of 20.3% in 2001 (Statistics Canada, 2003) and of nearly 25% in 2007 (Statistics Canada, 2010). While these statistics are troubling, they probably underestimate the actual burden of arthritis in Aboriginal populations owing to the fact that some people who are Aboriginal and who have arthritis are probably undiagnosed (Health Canada, 2003a).

The morbidity associated with arthritis is also higher in Aboriginal populations than in the general Canadian population. Notably, arthritis in Aboriginal populations tends to have an earlier age of onset. For instance, researchers in northern Ontario (Jacono, Jacono, Cano, Segami, & Rubin, 1996) found that 40% of patients who were identified as Aboriginal had onset before 30 years of age and only 8% had onset after 49 years of age, compared to 12% and 41% of those identified as Caucasian, respectively. In addition, outcomes for Aboriginal individuals with arthritis, including severity of disease (Barnabe et al., 2008) and rates of disability (FNC, 2005), seem to be worse. Arthritis carries significant burden in Aboriginal populations.

Understanding the Burden of Arthritis in Aboriginal Populations

Quantifying the actual burden of arthritis in Aboriginal populations is complex because of conceptual difficulties in defining what constitutes arthritis. Historically, the term *rheumatic disease* was used to describe the musculoskeletal conditions that are largely described as arthritis today (Reading, n.d.). While the category of rheumatic disease is no longer officially sanctioned, the term *rheumatism* is still used in some contexts. For instance, the 2002 RHS used the descriptors of arthritis and rheumatism. Some RHS reports collapse these two categories (e.g. the B.C. RHS; First Nations Chief's Health Committee, n.d.), while others do not (e.g. the Canadian RHS; FNC, 2005). Currently, the term arthritis encompasses a large, heterogeneous group of disorders that count more than 100; the most commonly known are osteoarthritis (OA) and rheumatoid arthritis (RA). However, the diseases that belong to the arthritis category are disputed. For instance, some consider fibromyalgia to be an arthritic condition while others argue that it is not (e.g. Edwards, Bingham, Bathon, & Haythornthwaite, 2006; Herrmann, Scholmerich, & Straub, 2000). It is likely that the term arthritis refers to a different catchment of disorders in different contexts.

Even though the conditions associated with the term arthritis vary in clinical presentation and treatment, all types of arthritis are typically grouped together for surveillance and research purposes because of similarities in pathology (joint degeneration), outcomes (pain, mobility restriction, depression, and fatigue) and the demographic profile of sufferers (Sui & Chui, 2004). In terms of demographics, arthritis is more common in women. Data from both the general Canadian population (Statistics Canada, 2010) and from First Nations peoples living on reserve (FNC, 2005) show that approximately 60% of people who have arthritis are women. Further, arthritis is more common in older people. For instance, among First Nations peoples living on reserve, the arthritis rate for people over 60 is 45.5%; this rate drops to 38% for individuals between the ages of 50 and 59, and to 22.1% for those aged 40 to 49 (FNC). The burden of arthritis is experienced differentially by Aboriginal peoples, women, and the elderly.

Chronic pain may be the most significant burden associated with arthritis. Arthritis sufferers experience ongoing and significant pain and pain is a cardinal symptom of arthritis (Edwards et al., 2006). For arthritis sufferers, pain is the best predictor of self-rated health (Cott, Gignac, & Badley, 1999). People with chronic pain end up with more disability (Scudds & Ostbye, 2001), poorer quality of life (Phillips, 2001), and more psychological disturbances (Currie & Wang, 2004; McWilliams, Cox, & Enns, 2003) than those with chronic illnesses that are pain-free. The presence of pain adds significant burden to the arthritis experience because the complexities of pain render challenges in its management. As argued by Clark (1999), "pain must be conceived as something more complex than sensation alone… biographical, social and cultural contexts in which it is located and experienced are essential both to fuller understanding and to appropriate care" (p. 727). Because of the importance of personal histories of pain and illness, including exposure to social models of pain, in shaping the pain experience, expressions of pain vary widely between population groups and even within those groups (Craig, 2009). Although there is a dearth of literature exploring chronic pain among Aboriginal populations, one study conducted in the United States found that American Indians with musculoskeletal pain tended to minimize or ignore their painful experiences and under-represent the degree of pain experienced when interacting with healthcare professionals (Kramer, Harker, & Wong, 2002). The complexities in understanding pain experiences add to the complexities of understanding arthritis experiences in Aboriginal populations.

Biomedical Perspectives of Arthritis in Aboriginal Populations

As noted in Chapter One, arthritis has been relatively unstudied in both mainstream and Aboriginal populations (Barnabe et al., 2008). Available research that considers Aboriginal populations tends to focus on RA. The bulk of this literature focuses on epidemiological studies, medications, or genetics (e.g. see Oen et al., 2005; Peschken et al., 2010). For example, a Medline search (performed January 16, 2006) with the key words American Native Continental Ancestry Group and arthritis revealed 53 results for the years 1990 to January 2006; of those results, 39 papers (74%) focused on genetic or physical factors associated with RA. Only one study was found with OA as the subject (i.e. Steinitz, Harvey, Berry, Reindl, & Correa, 2005). This study considered physical factors associated with the onset of OA. Research into the most common type of arthritis, OA, and research into the role of social factors, is rare.

This reality reflects the history of Aboriginal research, in which the research agenda has been based on investigator curiosity rather than the health needs of the population (Young, 2003). The persistent focus on genes warrants critical reflection. As argued by Fee (2006) and others (e.g. Lock et al., 2007), genes are, at most, co-producers of disease, interacting with elements outside the physical make-up of the patient (e.g. poverty, environmental contaminants, stress). The focus on genes without concomitant attention to those other elements perpetuates a reductionist and biomedical view of arthritis and suggests that the discourse on social determinants of health is still somewhat marginalized in the arthritis research arena. Because RA accounts for a relatively small proportion of the overall burden of arthritis, and because the role of the social determinants of health remains unstudied, arthritis is one chronic illness whose overall negative impact on the health and well-being of First Nations Canadians remains relatively untold. Arthritis in Aboriginal populations seems to be a “neglected health disparity”

(Ferucci, 2008, p. 956).

Although sparse, the available information about arthritis in Aboriginal populations suggests that more investigation into this chronic condition is warranted. While the difference in prevalence rates between Aboriginal/First Nations populations and the general Canadian population is troubling, perhaps even more troubling are the data that suggest poorer outcomes in Aboriginal/First Nations populations (e.g. more disability). These outcomes are related, at least in part, to issues surrounding access to and utilization of health services. For instance, First Nations peoples living in Winnipeg, an urban centre in the province of Manitoba, had lower rates of referral to specialists despite a higher burden of disease (Martens et al., 2005a). While the health system is probably only one factor influencing poor outcomes, its role may be significant.

Arthritis Health Services and the Canadian Health System

Institutions like healthcare systems, in any given society, are a product and reflection of that society (Lock & Gordon, 1988). The Canadian health system was originally constructed to reflect the foundations of Canadian society: capitalism, industrialism, and biomedicine (Gaines & Davis-Floyd, 2003). In this context, the body was viewed as a machine and disease was viewed as a defect in the body that could be fixed. The *expert* physician applied coveted knowledge to the body that was surrendered by the patient (Kirmayer, 1992). This approach spawned a health system that is hierarchically organized by disease categories and focused on a biomedical, reductionist, and technocratic view of the physical and observable causes of illness (Lock & Gordon).

Canada has been a leader in broadening the biomedical understanding of health and illness by promoting an understanding of the role of social factors on health and health outcomes. The Lalonde Report - *A New Perspective of the Health of Canadians* (1974) broadened ideas about determinants of health to include environment, lifestyle, and healthcare organization, in addition to human biology. Other Canadian reports that followed have positioned Canada as a leader in promoting the social determinants of health at the international level (Lavis, 2002).

While Canadian reports have been praised internationally, at home there has been little concrete action in creating strategies to attend to the social determinants of health and to reduce health inequities in Canada (Frohlich et al., 2006; Lavis, 2002; Raphael et al., 2008). This may be due, in part, to the way that the social determinants of health discourse has been taken up in Canada. For instance, while the international dialogue has often focused on living conditions as critical social determinants, in the Canadian healthcare sector more emphasis seems to be placed on lifestyle choices (Tuohy, 2007). The way this discourse has been taken up continues to marginalize social and structural influences on health in favour of a purely individualistic view of health (Raphael et al.). The individualistic view of health is reinforced by a North America-wide growing “supervaluation of the individual” (Gaines & Davis-Floyd, 2003, p. 5) and a neo-liberal orientation (Raphael et al.).

Currently, the *individual* with a health concern has been reconceptualized as a *consumer* whose actions impact healthcare’s bottom line. The consumer approach is in keeping with a business model of healthcare, underscoring fiscal constraint, which has resulted from marked reductions over the past decades in the federal government’s contributions to provincial healthcare services (e.g. Tuohy, 2002). Today, discourses of efficiencies and cost-effectiveness dominate the parlance of healthcare leaders and commentators as healthcare systems struggle with mandates to provide more/better services with proportionately less money. While the need to control healthcare costs is recognized by health systems the world over, some scholars argue that fiscal pressures are spawned by “the troubling phenomena of the medicalization of life, the commercialization of care and the power of the market to dominate the health care agenda" (Kenny, 2002, p. 1), which leads people to believe that more healthcare, rather than different healthcare, is required (Canadian Health Services Research Foundation [CHSRF], 2009). These scholars suggest that the dominance of the efficiency and cost-effectiveness discourses obscure a more basic need to clarify values about health and healthcare to determine policy priorities that could be carried out within the current financial situation (CHSRF; Kenny; Light, 1998).

A model for understanding the potential impacts of policy at the level of service provision is provided by Tuohy (2007) who notes that policy is "filtered through institutions and interests….and the very ways of thinking that prevail in a given society" (p. 113). The outcome of health policy is a product of dominant discourses in society and powerful interest groups (i.e. the Canadian Medical Association and the Canadian Healthcare Association). Policies that challenge institutions or the power of dominant interest groups are less likely to lead to significant change. Hence, the implementation of policies that can address the social determinants of health "has been woefully inadequate" (Raphael et al., 2008, p. 222) because they challenge the monopoly of the medical profession and the hospital system. In contrast, policies regarding super-individuation have had widespread impact because they are well-aligned with society-wide beliefs about free will and individual agency. Fiscal policies directed at constraint have been aided by a discourse that positions fiscal restraint as necessary and inevitable (Light, 1998). This discourse has saturated the Canadian public consciousness (CHSRF, 2009). Because the complex policy context tends to reproduce the entrenched status quo, introducing change into the health system is difficult.

Despite the difficulties in introducing change, some sectors of the system, like chronic illness management, have been able to do so. However, all change efforts are influenced by the same discourses that are operating in the broader system.

Chronic Illness (Self) Management

According to the Government of B.C., treatment for chronic conditions consumes 70-85% of the B.C. healthcare budget (B.C. Ministry of Health, 2002a). The significant costs associated with chronic illnesses have been a major driver in the push to develop effective ways of managing and preventing chronic illnesses (B.C. Ministry of Health, 2002a). However, most chronic conditions continue to be inadequately treated (Bodenheimer, Wagner, & Grumbach, 2002) as medical encounters focus on “treating acute flare-ups, rather than regular monitoring and prevention” (Centre for Health Services Policy Research [CHSPR], 2005, p. 1). This orientation to healthcare results from the biomedical foundation of the health system as well as remuneration practices for physicians. Most physicians operate as private practitioners in a fee-for-service arrangement with provincial governments (Kirby & Keon, 2004). As such, their income is based largely on the quantity of services provided, rather than quality. A B.C. survey of family physicians revealed that time, complexity, workload, remuneration, and human resources are barriers to the provision of comprehensive chronic illness care to patients (B.C. Ministry of Health, 2002b). The influence of context on physician practices (including the policy and regulatory climate) underscores the interconnectedness of barriers to quality health services.

While many Canadians experience difficulties in getting their chronic illness health needs met, some populations seem to experience healthcare inadequacies more than others. Not surprisingly, populations that experience other inequities in society (e.g. poverty) seem to also experience inequities in obtaining adequate care for their chronic illnesses. For example, healthcare inequities along gender lines have been documented; Hawker and colleagues (2000), in a large and detailed survey of Ontarians aged 55 years and older (n = 8,687 women and 4,528 men), found that women with arthritis had worse symptoms and greater disability but arthroplasty was underused by eligible and willing women at a rate three times higher than for men. Healthcare inequities related to the perceived race of the patient are explored in the last subsection of this review. Chronic illness management is socially embedded and subject to influence by social factors related to the patient and the healthcare provider (Paterson, 2000).

In an effort to improve and standardize care across populations, the B.C. Ministry of Health promotes care based on Wagner and colleagues' (Wagner, Austin, & Von Korff, 1996; Wagner et al., 2001) heuristic Chronic Care Model (CCM; B.C. Ministry of Health, 2005). The CCM identifies two critical components for improved patient outcomes: 1) an informed, activated patient, and 2) a prepared proactive practice team. Research into the effectiveness of the CCM has shown that the model can be very effective, however, real system redesign must be incorporated for improvements in outcomes to be realized (Wagner et al., 2001).

There have been some significant changes in the healthcare system towards the vision of an informed and activated patient. Historically, healthcare professionals, especially physicians, were positioned as experts and authoritarians. This model, while perhaps suited for acute illness, is less well-suited to deal with the complex bio-psycho-social issues faced by people with chronic conditions (Watt et al., 1999). A shift towards empowering patients to be experts in their own conditions has been occurring over the past several decades. For instance, in a report on a comprehensive review of qualitative research (published between 1980 and 1996) on healthcare relationships in chronic illness, the authors describe a "dramatic shift that has occurred in the reconceptualization of client from patient to partner" (Thorne & Paterson, 1998, p. 177). However, conceptualizing the person with chronic illness as "strong, powerful, and competent" (Thorne & Paterson, p. 177) may be misrepresenting the complexity of the experience of having a chronic illness and may be obfuscating the reality that most people with chronic illnesses will continue to need to seek help from experts, and many may be overwhelmed with the complexities of managing their condition (May, Montori, & Mair, 2009; Thorne & Paterson). In addition, this shift runs the risk of perpetuating an individualistic view of health while marginalizing the social determinants of health and, in doing so, indirectly blaming the individual for his/her health status (Newman et al., 2007).

A hallmark of the shift towards empowering the patient has been the ubiquitous promotion of the concept of *self-management* across B.C. and elsewhere in Canada. For instance, Vancouver Coastal Health's (VCH) website information about chronic disease notes that "research…has come up with a way for people to deal with the problem [of chronic disease]… self-management, the approach is to teach people how to control and minimize symptoms and the effects of their chronic condition…" (VCH, n.d.). The self-management movement is a global phenomenon that began in the United States of America (USA) in the early 1980s with the Arthritis Self-Management Program (ASMP; Lorig, 1981). Today, variations of this program have been applied globally owing to its success in reducing pain and healthcare costs for arthritis sufferers (e.g. Lorig, Lubeck, Kraines, Seleznick & Holman, 1985; Lorig, Mazonson & Holman, 1993). In B.C., the ASMP was modified to be applicable to a wider range of chronic illnesses. Three programs have been developed: the Chronic Disease Self-Management Program, the Chronic Pain Self-Management Program, and the Diabetes Self-Management Program (Centre on Aging, n.d).

However, the self-management movement has not been without criticism. Critics have noted that self-management may not be appropriate for everyone. For example, in a study of patients recruited from primary care to participate in an ASMP, only 12-13% of patients with arthritis agreed to participate, and out of those who agreed there was a 43% attrition rate (Solomon et al., 2002). Additionally, results showed that among those who participated, no benefits in pain, disability, self-efficacy, or mental health and vitality, as compared to baseline, were found. The authors explain these results, which are contrary to most other findings, by noting that these participants were actively recruited in contrast to usual participants in ASMPs who independently volunteer to participate and thus can be considered to be highly motivated. These findings suggest that self-management may appeal to a narrow segment of society. The self-management movement has also been criticized for being driven primarily by economic considerations (Thorne & Fraser, 2002), an off-loading of costs and responsibility from the healthcare system to the patient. There is mounting evidence that federal reductions in healthcare spending may be directly transmitted to individuals in terms of out-of-pocket spending. As described by Raphael and colleagues (2008), liberal ideologies underlying the self-management movement serve to place responsibility for health squarely upon individuals rather than accounting for the well-known and evidenced social determinants of health that result from social and structural inequities between population groups. Thus, the ubiquitous self-management movement may be contributing to ongoing inequities by diverting responsibility for health away from those societal structures that differentially create situations that promote ill health.

Changes in the roles and responsibilities of patients and providers, as promoted by the CCM, reflect the effects of evolving discourses and social pressures. Fiscal pressures may well have contributed to the key role that self-management has assumed because if people can be taught to manage their own illness, then the costs to the system ought to be reduced dramatically. However, as suggested by the research, no amount of teaching is likely to offset the potency of the social determinants of health in influencing the experience and management of chronic illness (Gately, Rogers, & Sanders, 2007). While efforts to empower patients are a step in the right direction, there is considerable room for improvements in chronic care.

Arthritis Services: Changing in Which Direction?

Arthritis is a chronic illness with particular challenges in its management. As noted earlier, the presence of chronic pain contributes to the complexity of arthritis management. Additionally, there are complexities in managing the underlying processes of joint deterioration because of their broad etiologies. As a result, arthritis care commonly involves family practitioners and specialists such as orthopedic surgeons and/or rheumatologists. In addition, in many Canadian urban centres, specialized healthcare programs have been set up to provide arthritis-specific services. Many tertiary programs are organized around specific medications (Hills, personal communication, March 2006) for the purposes of research and also for patient monitoring, given the high potential for serious complications and side-effects that are associated with many of the newest medications (e.g. Wolfe, Michaud, Gefeller, & Choi, 2003). In this way, the advancement of pharmaceutical knowledge has been an important driver in the evolution of arthritis services. In addition to a specific focus on new and emerging pharmacotherapy, some tertiary centres offer access to multidisciplinary teams who intend to provide comprehensive care to people with complex arthritis.

While comprehensive care may be available in tertiary settings, it seems elusive in primary care. For instance, research from Ontario suggests that arthritic patients do not get comprehensive care, meaning care that goes beyond addressing a single facet of the illness. Only 51% of patients surveyed (n = 382) received recommendations for all (pharmacotherapy, exercise, and weight loss if needed) well-evidenced treatment options (Glazier et al., 2003). In recommending treatment for arthritis, family physicians may be most comfortable with prescribing medications. For instance, a study of Ontario’s family practitioners (n = 529) reported that while 61% of participating physicians correctly identified appropriate pharmacology in response to a vignette of knee osteoarthritis, less than 1/3 recommended exercises and/or rest (Glazier et al., 1998). Indeed, medications are the most commonly prescribed treatment for arthritis (Anis et al., 2005; Glazier et al., 2003).

Arthritis medications come in two main categories: disease altering (useful for RA and other inflammatory arthritic conditions) and symptom control (to reduce pain and swelling). Over the past several years, new disease-modifying anti-rheumatic drugs (DMARDs), especially effective when introduced early in the trajectory of the disease, have been developed and marketed. First Nations peoples may be less likely to benefit from this latest research since they are less likely to seek healthcare for their arthritis early in the disease process (McGowan & Green, 1995). Indeed, many arthritics may not be benefitting from the newest drugs. A recent survey in B.C. demonstrated that less than 1/2 of the RA population received a prescription for DMARDs over a five-year period and over a one-year period only 31% had received such a prescription (Lacaille, Anis, Guh, & Esdaile, 2005). The most important predictor for the prescription of DMARDs was care by a rheumatologist; those not been seen by a rheumatologist were unlikely to have received a prescription.

Access to a rheumatologist is dependent on family physician referral. Referral patterns have been found to be influenced by patient characteristics such as income level and perceived socio-economic status and perceived ethnicity (Hurley & Grignon, 2006; van Doorslaer, Masseria, & Koolman, 2006). For instance, Canadians with higher incomes were found, in a cross-country comparison of physician utilization, to be more likely to have visited a specialist, and to have visited specialists more often, as compared to lower income Canadians (van Doorslaer et al.). In Manitoba, First Nations peoples were found to have fewer contacts with specialists than the general population (specialist visit rate was 30% lower); the urban areas with the poorest health status were found to have the lowest specialist referral rates (Martens et al., 2005a). Further, another study in Manitoba revealed that Aboriginal patients with arthritis were seen by specialists less often than their non-Aboriginal counterparts despite more severe disease (Barnabe et al., 2008). Although arthritis care has evolved to include specialist care, there are inequities among Canadian social groups in terms of ready access to this component of arthritis care.

Medications and specialist care remains focused on altering the trajectory of arthritis, especially RA. While much attention has been focused on managing the trajectory of arthritic diseases, there has been much less focus on the management of the symptoms of arthritis, particularly the symptom of pain. Pain remains widely unaddressed in arthritic as well as in other chronic conditions. However, pain continues to be a hallmark feature of arthritis.

The Conundrum of Chronic Pain Management

According to many Canadian pain management experts, chronic pain is undertreated in Canada (e.g. Canadian Pain Society, 2010; Jovey et al., 2003; Weidner, 2010). A number of intersecting factors have led to this reality. One factor is the lack of research evidence on what works for chronic pain management (Noble et al., 2010). While there continues to be a fair amount of research into medications for chronic pain, research into other ways to manage chronic pain is underdeveloped (Gallagher, 2003; Phillips et al., 2008). Even in the area of medication use, available research is relatively sparse. For instance, the recent Canadian guidelines on the use of opioids for chronic pain relied heavily on expert opinion because of the lack of research evidence (Furlan, Reardon, Weppler, 2010). A second factor that has been repeatedly raised is the lack of physician education in this area. According to some pain experts, Canada is in desperate need for “increased education in chronic pain management at the undergraduate and postgraduate level” (Morley-Forster, 2005, p. 1103). A final factor that seems to be inhibiting chronic pain management has been described as *opioid phobia* (Gallagher, 2003; Weidner). This is the fear of addiction and misuse of narcotics that is commonplace among physicians (Noble et al.; Weidner) and patients alike (Moulin, Clark, Speechley, Morley-Forster, 2002; Noble et al.). While the rate of addiction to prescription opioids has remained relatively stable over the past decades and represents only about 1% or less of prescription users (Nobel et al.), rates of diversion are reported to have increased substantially over the past several years (e.g. see Furlan et al.). The difficulty in defining appropriate chronic pain treatment is due, in part, to an overall dearth of “adequate and appropriate policy frameworks” (Phillips et al., p. 171) to promote comprehensive chronic pain management strategies.

Since medication administration is the most common approach to chronic pain management and narcotics are one of the most effective drug choices in this regard (Noble et al., 2010; Passik, 2009), the tensions between the desire to improve chronic pain control and the desire to reduce the effects of narcotic misuse continue to substantially shape practice. For instance, the new Canadian Guideline on the Safe and Effective use of Opioids for Chronic Non-cancer Pain (Furlan et al., 2010) was inspired primarily to deal with considerable increases in the rates of opioid prescription in Canada (rates increased 50% during the years 2000 to 2004) and the perceived concurrent misuse. However, there is no mention of the potential for these numbers to reflect a move towards better chronic pain control in Canada. For, as pain expert Dr. Roman Jovey notes in response to the new Guideline, the problem of under-treatment is more significant than the problem of misuse (Weidner, 2010). Historically, conservative policy on prescribing narcotics has been criticized by pain experts. For instance, the B.C. Medical Association's policy to deter narcotic over-prescription applies a standard acceptable level of narcotic prescription to all family physicians regardless of their patient population. There is no attempt to ascertain whether the standard is appropriate for any specific practice (e.g. Goldman, 1996; Hagen, Flynne, & Macdonald, 1996; Jovey, 1996). Hence, current opioid policy in B.C. and in Canada seems to constrain the use of one of the most effective chronic pain medications that is available.

While chronic pain management is generally inadequate, research has repeatedly revealed idiosyncratic and wide variations in physician practices towards chronic pain (e.g. see Gallagher, 2003; Rashiq, 2005). Importantly, the literature indicates that persistent inequities, with respect to the quality of pain management, exist between some social groups (e.g. see Lebovits, 2005). These inequities are related to the fact that pain is a subjective experience; physicians have no objective way of substantiating pain complaints (Craig, 2009; Phillips et al., 2008). Hence, in most chronic pain encounters, physicians judge the credibility of the patient based on their relationship with the patient, which is subject to interpersonal dynamics often related to the social group to which the patient and provider belong (Craig; Hoffmann & Tarzian, 2001). Indeed, chronic pain management variation may provide a key view into the way that interpersonal dynamics influence healthcare practices more broadly.

A significant factor that seems to influence chronic pain management decisions is the *race/ethnic/cultural* background to which the patient is ascribed[14]. In the USA, a body of literature has documented *racial disparities in pain management* (e.g. an entire issue of Pain Medicine [Lebovits, 2005] was devoted to the topic). This research documents that visible social groups (Blacks and Hispanics were most often studied) receive a poorer quality of pain care as compared to Whites across all treatment settings and types of pain. Importantly, the bulk of the literature published in this area is derived from the USA where tension along racial lines has been well documented. There is a dearth of literature on this topic in the Canadian context despite a preponderance of evidence, coming from other topic areas, indicating that Canadian healthcare professional judgments and decisions are influenced by racializing processes (see final section of this review).

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[14] While the majority of the research reports on pain management variations based on race/ethnicity/culture, it is likely that what matters is the background to which the provider believes the patient belongs, not the actual background of the patient. Further, it is the interpersonal processes that happen when the provider categorizes a patient (i.e. the provider applies social group stereotypes to the patient) that are the most powerful shapers of

While differences in chronic pain management decisions made by providers have been well studied in terms of the difference that the assumed race of the patient makes on outcomes, the same findings have been shown across a number of axes, including the (assumed) gender and socio-economic status of the patient (e.g. Hoffman & Tarzian, 2001; Rusconi, Riva, Cherubini, & Montali, 2010). Unfortunately, the data suggest that people who tend to be disadvantaged in society in general are also disadvantaged in chronic pain management decisions made by providers (Sullivan & Eagel, 2005). However, more sophisticated studies have shown that the (reported) background of the provider also influences the decisions that are made (Nampiaparampil, Nampiaparampil, & Harden, 2009; Safdar et al., 2009). These findings underscore the complexity of the chronic pain encounter and suggest that interpersonal dynamics between patient and provider are influenced by who they are, including their positioning with respect to various social groups.

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behaviour. These processes of racialization are described in some detail in the last section of this review. In this section I follow the use of the terms race, ethnicity, and culture as they are used in these articles.

There is every reason to expect that pain management in arthritis will be subject to the same powerful interpersonal dynamics. Although the clinical picture of arthritis usually includes some features that can be objectively determined (e.g. tender point analysis and x-rays to reveal joint damage), research suggests that the level of pain is not well correlated with objective findings (e.g. see Perruccio, Power, Denise, & Badley, 2005; Zhang, Robertson, Jones, Dieppe, & Doherty, 2008); the pain dimension of arthritis evolves somewhat independently of the joint effects. Hence, Aboriginal patients with arthritis (or rather patients who are constructed as Aboriginal by their provider) may be at a disadvantage in their ability to receive quality pain management practice. However, the particular interpersonal dynamic that evolves between patient and provider are probably key in terms of the actual outcomes of healthcare encounters.

Aboriginal Peoples' Encounters with the Health System

Research has consistently shown that high proportions of Aboriginal peoples experience a multitude of barriers to accessing quality healthcare in Canada (Adelson, 2005; Bowen, 2000; Browne, 2007; Browne et al., 2011; McCall, Browne, & Reimer-Kirkham, 2009; O'Neil, 1989; Shah, Gunraj, & Hux, 2003). For example, *status*[15] First Nations peoples access general practitioners and specialists at rates that are not commensurable with the higher burden of illness experienced by First Nations peoples; status First Nations peoples access general practitioners at a rate similar to the general population (B.C. PHO, 2009; Barnabe et al., 2008; Martens et al.,

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[15] The federal government maintains a list of First Nations individuals who are registered as *Status Indian* and hence are eligible for federal programming. Eligibility to register as Status is complicated because Status is classified in two distinct categories depending on the presence of a non-Status parent, history of registration (and parent's registration), date of birth and gender. Aboriginal leaders have long disputed the registration process as unfairly excluding large numbers of Aboriginal peoples and of perpetuating control of Aboriginal identity outside the hands of Aboriginal peoples. See Assembly of First Nations & Indian and Northern Affairs Canada (2008) for a comprehensive discussion of the topic.

2005a) despite higher morbidity. In addition, as discussed above, Aboriginal peoples have lower rates of specialist utilization than the general Canadian population (Barnabe, et al.; Marten et al.). Further, higher rates of hospitalization for health issues that are typically handled in family practice probably reflect barriers to accessing primary care (B.C. PHO; Browne et al.; Shah et al.). These statistics suggest that access to care is problematic for Aboriginal peoples at the population level.

Historically, the principal barrier to healthcare for Aboriginal peoples has been conceptualized as one of availability of health services because Aboriginal peoples were characterized as living primarily in remote and rural communities (e.g. Canadian Institute for Health Information [CIHI] 2004; RCAP, 1993). Today, since more than 50% of Aboriginal peoples live in urban locations (both on and off reserve), physical access to services is less likely to be a barrier (Browne, McDonald et al., 2009). Further, those living in remote or rural areas sometime show higher rates of accessing both general practitioner and specialist care than their urban counterparts (Martens et al., 2005a). Since statistics seem to refute a lack of availability of services as a primary determining factor for problematic access, the *nature* of health services, for instance the way services are organized and delivered, has been positioned as a significant barrier to utilization of health services by Aboriginal peoples.

Culturalist Discourses and Racializing Practices in Healthcare

A large body of literature suggests that Aboriginal peoples' experiences and/or perceptions of racism, discrimination, and/or marginalization during encounters with the health system are a barrier to healthcare utilization (e.g. Adelson, 2005; Bowen, 2000; Browne et al., 2011). Critical analysis reveals that healthcare providers are influenced by dominant social discourses which often construct Aboriginal peoples in negative ways (Browne, 2005, 2007;

Fiske & Browne, 2006; Furniss, 1999; O'Neil, 1989; Tarlier, Browne, & Johnson, 2007). Discourses that construct Aboriginal peoples in negative ways intersect with culturalist discourses, which are also prominent in healthcare (e.g. Browne, Varcoe, et al., 2009), to reinforce the appropriateness of the categorization of Aboriginal patients, in terms of negative stereotypes, by healthcare providers. As healthcare providers draw on the assumptions they have about Aboriginal peoples, microlevel interactions in healthcare are shaped by wider macrolevel social and historical relations.

Discourses that construct Aboriginal peoples in negative ways are rooted in colonial ideas that persist today (Browne, 2005, 2007; Furniss, 1999). A particularly powerful discourse about First Nations peoples that shapes healthcare encounters is the discourse that First Nations peoples "get everything for free" (Browne et al., 2011, Newhouse, 2004). This widespread misconception has resulted from federal funding and programming (though limited) for status[16] First Nations peoples, related to the fiduciary responsibilities and treaty rights that the federal government has towards First Nations peoples (Assembly of First Nations [AFN], 2005a)[17]. One such program relevant for this discussion is the Non-Insured Health Benefits (NIHB) program, which provides supplementary benefits to cover the cost of some medications and healthcare devices, some dental care, and medical transportation. While this program has enabled some First Nations peoples to access some medications, medical appointments, and equipment that would otherwise cost them out-of-pocket, it provides only small-scale financial relief for some First Nations peoples who are less likely than other Canadian residents to have other forms of health insurance (Luffman, 2005), less likely to have adequate incomes (B.C. PHO, 2009), but more likely to have higher healthcare costs related to the higher burden of illness. Additionally, fiscal constraint occurring over the past years has resulted in a steady stream of benefits that have become ineligible for reimbursement (AFN, 2005a; Bowen, 2000; Lemchuk-Favel, 1999). On the other hand, some new items have been added to the list of eligible benefits over the years. For instance, some of the new DMARD drugs for arthritis have been added. However, NIHB has been repeatedly criticized by the AFN because approval processes are complex and in many cases rejection rates are high (e.g. AFN). Regardless of the realities of the limitations of these programs, the discourse that First Nations peoples "get everything for free" can create resentment towards First Nations peoples in the minds of some healthcare professionals (Newhouse; Tang & Browne, 2008).

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[16] Since First Nations people who have status account for only about 60% of the Aboriginal population in Canada (Indian and Northern Affairs Canada [INAC], 2007), there are many Aboriginal individuals who are not eligible for this benefit.

[17] A range of funding and programming is provided by the federal government. For example, benefits are available for some medical supplies. In addition, financial support is provided for elementary, secondary and some post-secondary education. Other funding provided includes some assistance for housing on reserves (INAC, 1999).

The persistent presence of such colonial discourses in Canadian society supports negative stereotypes of Aboriginal peoples that play out in healthcare encounters. Two stereotypes that have been identified as influencing some healthcare encounters are the *drunken "Indian"* (Browne, 2007; Furniss, 1999) and the Aboriginal person as *drug seeker* (Browne; Browne et al., 2011; Tang & Browne, 2008). These colonizing images remain salient even though research has demonstrated that alcohol and prescription analgesic use is not more common in Aboriginal communities than it is in other communities with similar socio-economic status (i.e. Anderson & McEwan, 2000). The image *drunken Indian* has particular relevance to Aboriginal individuals who have mobility difficulties (as in the case of some people with arthritis) since an awkward or imbalanced gait can be mistakenly attributed to alcohol consumption by a healthcare professional who is unaware of how dominant discourses can be taken up to influence care. The second image has relevance for Aboriginal individuals with chronic pain. Research has shown that some healthcare providers consciously or subconsciously assume that Aboriginal peoples are at risk for narcotic abuse and hence individuals who are Aboriginal are at risk of having their complaints of chronic pain dismissed and their requests for pain medications viewed with a high degree of suspicion (Browne; Browne et al.). These colonizing images can shape providers' view of Aboriginal patients, contributing to miscommunication, social distancing between provider and patient, and less than optimal care (Browne; Tarlier et al., 2007).

The uptake of colonizing images by healthcare professionals intersects with culturalist discourses that are common in healthcare today. Culturalist discourses are the "complex practices and ideologies that use popularized stereotyped representations of culture, often conflated with ethnicity, as the primary analytical lens for understanding presumed differences about various groups of people" (Browne, Varcoe et al., 2009, p. 170). Although the need for healthcare professionals (especially nurses) to attend to the patient's culture has been widely promoted for the past few decades (e.g. Helman, 2000; Leininger, 1991), and remains an important component of good patient care, critical analyses of approaches to cultural assessment/interpretation and the corresponding culturalist discourses have shown that most current approaches foster a view of culture as static and uncontested, and as uniformly applicable to all people who are assumed to belong to the cultural group (Brown, Varcoe et al.). Further, as culturalist discourses position ethnocultural categories as key determinants of health behaviours (Browne & Varcoe, 2006; Gustafson, 2008), they obscure other, often more potent, determinants like poverty and lack of education. Hence, culturalist discourses contribute to an interpretation of behaviours as stemming from cultural norms when this may not be the case. For instance, in a study of nurses, Browne (2007) found that quiet behaviour in women patients who were Aboriginal was ascribed by nurses to a cultural norm rather than possibly reflecting a power imbalance and/or a learned response to colonial teachings of subordination. Hence, culturalist discourses can draw healthcare professionals' assessments away from a patient's resources for health and other social and structural barriers to effective care.

In taking up culturalist discourses, healthcare professionals tend to categorize patients by their assumed cultural (often collapsed with ethic and/or racial) group (Brown & Varcoe, 2006; Gustafson, 2008). Such categorization involves the process of racialization, which is inclusive of the ways in which "racial categories are constructed and how *constructions are used* in everyday social encounters to *categorize* people in order to interpret what they do and say" (Anderson, 2006, p. 10, emphasis in original). In the process of racialization, health professionals reinforce the naturalness and usefulness of understanding people and their behaviours in terms of their assumed race-based social group (Anderson, 2000). When an Aboriginal patient is racialized, they are often constructed as inferior Other[18], stigmatized and disadvantaged as negative stereotypes, and discourses are applied. Although this disadvantaging is often subtle and invisible, it results in structural inequalities, often "regarded as natural or unavoidable from the point of view of the dominant culture" (Chapman & Berggren, 2005, p.153). Colonizing images, applied through racializing practices, intersect with culturalist discourses to result in a situation whereby Aboriginal peoples are at high risk for experiencing uncomfortable, unhelpful, and potentially unsafe healthcare encounters.

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[18] In his revolutionary writing of Orientalism, Said (Said, 1979) describes the process of *Othering*, in which a dominant cultural population, through systematic and systemic characterizations of another group as inferior, creates and then perpetuates its position of advantage.

Improving Healthcare for Aboriginal Peoples?

In response to both health inequity statistics and calls for attention to marginalizing and discriminatory healthcare practices, healthcare systems across the country have embarked on initiatives to improve healthcare for Aboriginal peoples. These initiatives are perhaps reflective of the shifting terrain of healthcare for Aboriginal peoples as demonstrated (in B.C.) by the Transformative Change Accord (2005), an agreement signed between the Province of B.C., the Federal Government and the Leadership Council representing the First Nations of British Columbia, intended to address health and social inequities, issues pertaining to Aboriginal rights and title, and the quality of relationships between these parties. In southern B.C., like most other regions, an Aboriginal Health Strategic Initiative (VCH, 2009) has been developed and implemented. Central to initiatives like this are strategies to make health services more *culturally sensitive*, *culturally appropriate* or to improve the *cultural competence* of healthcare providers. Each of these terms, while varying slightly in their meaning, has at their foundation a desire to increase healthcare professionals' understanding of the culture of Aboriginal peoples. The goal of these kinds of strategies is to enable healthcare providers to tolerate, respect, and even appreciate Aboriginal culture. However, because these strategies tend to be underpinned by culturalist ideology (Browne, Varcoe et al., 2009) and a narrow view of culture (Browne & Varcoe, 2006), they do not always address the root causes of health and healthcare inequities and processes of racialization and Othering.

Conceptualizations of culture in healthcare. Since the 1980's many healthcare theorists and scholars have identified the role of culture in shaping health and health practices of patients (Lynam, 2006). As follows, over the ensuing years, healthcare providers have been urged to attend to the culture of the patient in order to provide competent care (e.g. Johnson, 2004; Rodriguez, 2003; Searight, 2005). While these approaches to healthcare have been useful in some instances, critical reviews of these approaches suggest that when the concept of culture is understood in a narrow way and when cultural assessments are not balanced by attention to other social factors, patients can be dis-served by such approaches (Browne, Varcoe et al., 2009).

In a narrow view (as opposed to a critical view), culture is assumed to be a set of static beliefs, values, and customs that have remained untouched over the years, existing in a "timeless and unchangeable vacuum outside of patriarchy, racism, imperialism, and colonialism" (Razack, 1998). According to Newhouse (2004), in this narrow view, Aboriginal culture (often assumed to be equivalent across contexts) is seen as "all singing and dancing" (p. 12). Such a view encourages healthcare professionals to engage with Aboriginal peoples as historical colonial subjects who encompass the negative colonial images discussed above. In contrast, a critical view of culture promotes an understanding of culture as complex, shifting, and relationally enacted (Allen, 1999; Doane & Varcoe, 2005). Thinking critically about culture underscores an awareness that popular views of culture are often underpinned by colonial and neocolonial discourses. Critical views of culture promote an understanding that any particular culture cannot be easily disentangled from the social, political, and economic environment (Smye, Rameka, & Willis, 2006). As such, patient experiences need to be situated within the larger socio-political and economic environment to avoid the trap of making sense of differences in terms of racialized notions.

When health systems undersign culturalist approaches, such as cultural sensitivity, culturalist understandings (i.e. narrow views of culture) are promoted. In that process, racializing practices of health professionals can be reinforced. While current cultural sensitivity approaches that are designed to enhance healthcare professionals' appreciation of Aboriginal culture may perhaps help contest some of the negative stereotypes, such approaches risk replacing one stereotype with another. In doing so, Aboriginal peoples continue to be essentialized and categorized into one homogenous group. Further, culturalist approaches reinforce healthcare professionals' categorization of some patients as cultural Other (or *them*) in comparison to healthcare professionals (or *us*), the dominant cultural norm (Narayan, 2000). In the context of negative colonial images of Aboriginal peoples, categorizations of Aboriginal patients as Other typically signal an inferior positioning in relation to the healthcare professional (Browne & Varcoe, 2006), reinscribing colonial power imbalances and disadvantaging Aboriginal patients in the healthcare encounter. Many authors make the point that these actions by health professionals are not typically intentional; they occur unwittingly (e.g. Anderson, 2000; Bonham, 2001; Browne, 2005; Greiger, 2001). Without an awareness of the ways in which dominant discourses and stereotypes are active in healthcare encounters, healthcare professionals are unlikely to be able to address dynamics that disadvantage Aboriginal patients. Critical analyses of culturalist strategies to improve healthcare for Aboriginal peoples point to a need for a critical view of the term *culture* (Browne, Varcoe et al., 2009).

Cultural safety. As a means to address some of the shortcomings in culturalist approaches to healthcare, the notion of cultural safety has been promoted in some healthcare contexts. First developed in New Zealand by Maori nurse leaders as a means to prevent situations where people from a one ethnocultural group feel demeaned, diminished, or disempowered during healthcare encounters (Ramsden, 1993), the concept has been used in a number of Canadian contexts. The concept of cultural safety is based on post-colonial theories, which draw attention to the ways in which social, historical, and economic structures and processes, arising from the colonial history and neocolonial present, contribute to inequities

(Browne, Varcoe et al., 2009; Ramsden, 2000; Smye et al., 2006). Cultural safety is underpinned by a critical view of culture and as such it encourages healthcare professionals to attend to power imbalances and social-historical factors when working in contexts where cultural differences are perceived (Ramsden, 2000). Drawing on critical views of culture, cultural safety provides a framework to promote equitable healthcare relationships and to attune healthcare professionals to the complex context of their patients' lives.

A cultural safety approach in healthcare has the potential to positively shape healthcare encounters in a number of ways. First, cultural safety promotes critical consciousness in healthcare providers (Smye et al., 2006). In doing so, healthcare providers become aware of "mediating sociopolitical, economic, and historical forces" (p. 144) that shape healthcare encounters, health systems, and health and illness experiences. By extension, healthcare professionals can be aware of their own roles in reproducing and perpetuating inequitable relations and hence avoid unwittingly marginalizing or disadvantaging patients. Second, cultural safety promotes an awareness of processes of racialization, Othering, and drawing on assumptions, in order to disrupt culturalist discourses (Browne, Varcoe et al., 2009). Finally, cultural safety promotes a moral and ethical view (Smye et al.) of healthcare systems and healthcare relationships. It serves as a reminder of the moral obligation that healthcare systems and healthcare providers have to redress health and healthcare inequities. As originally conceptualized by Ramsden (1993, 2000) and now others (e.g. Anderson et al., 2003; Browne, Varcoe et al.; Reimer-Kirkham et al., 2002), the ultimate appraisal of whether or not a healthcare encounter has been culturally safe belongs to the patient.

While a focus on cultural safety seems to hold considerable promise to improve healthcare encounters and thus the availability of quality services, it has not always been taken up in the ways described here. The predominance of culturalist discourses in healthcare has made critical interpretations of culture difficult to take up (Browne, Varcoe et al., 2009). However, a concerted program of cultural safety education for healthcare professionals has the potential to disrupt culturalist discourses (and thus racializing practices) in healthcare (Browne, Varcoe et al.). In doing so, healthcare quality for Aboriginal peoples (and others) can be improved as healthcare professionals are encouraged to view culture critically, appreciate the role of social context, and attend to unequal power in healthcare encounters.

Summary of, and Gaps in, the State of Knowledge

Arthritis is one of the most common of chronic illnesses in Aboriginal populations and yet this review of the literature shows that it is relatively unstudied. The high prevalence of arthritis in Aboriginal populations is reflective of the health inequities experienced by Aboriginal peoples as compared to the general Canadian population. The social determinants of health are clearly relevant in shaping the health status of Aboriginal peoples. Difficult living conditions, including high rates of poverty, intersect with the ongoing marginalization of Aboriginal peoples within Canadian society to distinctly disadvantage many Aboriginal peoples in terms of the goods and resources necessary for health.

Individuals with arthritis, who identify as Aboriginal, may have difficulty getting their health needs met. This is related, in part, to the challenges the system has in addressing the needs of individuals with chronic illness. Chronic illnesses have emerged as one of the premier challenges for the health system in general and for health services for Aboriginal peoples (Reading, n.d.). In an effort to address the burden of chronic illness, in B.C. the Chronic Disease Self-Management Model has been widely promoted. Patients are expected to take control of their illness, which, as noted by critics, underscores an individualistic approach for health and, in doing so, off-loads some responsibility for care from the system and deters attention from the social determinants of health. As such, the effectiveness of these approaches in meeting the health needs of First Nations peoples with chronic illness is questionable.

While all individuals with arthritis may have difficulty getting their health needs met, individuals who identify as Aboriginal may be at a special disadvantage because of the many barriers to access and utilization of quality services for Aboriginal peoples in Canada. The fact that chronic pain is a cardinal symptom of arthritis may further complicate the ability of First Nations peoples to receive quality care, since pain management by healthcare professionals has been found to be shaped by racializing practices. Aboriginal peoples are commonly judged in ways that disadvantage them in terms of obtaining optimal healthcare. While barriers to the access and utilization of care have been broadly documented, research into the actual experiences of First Nations peoples, as they manage their arthritis and access healthcare, is under-developed. The effectiveness of the health system in meeting the needs of First Nations peoples with arthritis is largely unknown.

This research aimed to attend to these gaps in knowledge by pursuing answers to the following research questions (as originally listed on page ten):

1) What are the health and healthcare experiences of First Nations peoples with arthritis who reside in an urban reserve community in B.C.?
2) What shapes their utilization of arthritis health services?
3) How does the organization and delivery of arthritis health services affect the ability of these services to be aligned with the experiences of First Nations individuals with arthritis?
4) What recommendations can be made for arthritis health services?

CHAPTER THREE: THEORETICAL PERSPECTIVES, METHODOLOGY, AND METHODS

Background for the Research

In Canada, community-based participatory research (CBPR), based on local empowerment within the research process, has become the gold standard for research within Aboriginal communities (Fletcher, 2003). This reflects both the growth in the political autonomy of Aboriginal peoples (Castellano, 2000; Fletcher) and the desire of academics to be *of use* to the Aboriginal communities with which they work (Haig-Brown, 2001)[19]. The endorsement of CBPR is a response to the history of research with indigenous populations across the globe, where researchers often violated trust, exploited, misrepresented, and declared the reality of those they considered Other (Battiste, 2008: Haig-Brown; Tuhiwai Smith, 1999). While CBPR may not be the only acceptable model of research within Aboriginal communities, its strength is that it acknowledges the need for knowledge to be coproduced within the context of a collaborative relationship between researchers and communities.

Among indigenous scholars (e.g. Bartlett, Iwasaki, Gottlieb, Hall, & Mannell, 2007; Battiste 2001; Tuhiwai Smith, 1999, 2005) and non-indigenous scholars (e.g. Prior, 2007; Smye et al., 2006), there has been a call for research with indigenous peoples to be not just collaborative, but to be decolonizing. Decolonizing research privileges indigenous perspectives in the research process and demands ethical research protocols (Tuhiwai Smith, 1999). Such an orientation is required to counter the potential for research to contribute to the project of colonization (Tuhiwai Smith). As noted by Smylie (2005), "it is only through an approach of mutual understandings, respect and partnership that academic research will be able to contribute to improving the health outcomes in First Nations, Métis and Inuit communities" (p. 997).

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[19] Some scholars have noted that there are risks associated with academics' desire to be "of use" to the populations with which they conduct research (e.g. see Reimer-Kirkham & Anderson, 2010). A sense of obligation to the community can encourage researchers to act as advocates for the community, placing them in tension with their role as analyst. The role of advocate must be problematized because it carries an undertone of unequal power relations (which could limit the agency of participants) and because the underlying ideological foundation of the researcher's drive for advocacy is often unexamined. Further, tensions can arise between the expectations of communities, with respect to research outcomes (and advocacy), and the drive for scientific rigor. Hence, there is a need for researchers to reflexively consider the ways in which they are "of use" to communities and the degree to which their actions could impede the scientific integrity of the research process.

Both decolonizing methodologies (Tuhiwai Smith, 1999) and CBPR (Fletcher, 2003) require a critical approach to research and science. Such an approach acknowledges that "all inquiry is political" (Fletcher, p. 32) and creates spaces for locally-derived knowledge regardless of the particular ontological and epistemological perspective. Hence, both decolonizing methodologies and CBPR are underpinned by critical theoretical perspectives.

Theoretical Perspectives

In this study, a design of CBPR was theoretically grounded in two theoretical perspectives, post-colonial feminism (PCF) and Aboriginal epistemology (AE), to inform a decolonizing approach. While these two theoretical perspectives flow from distinct epistemological and ontological perspectives, they are overlapping and complementary and together provide a broad and comprehensive vantage point for understanding complex issues encountered in health and healthcare research from a social justice perspective. For example, a primary aim of research from a PCF perspective is to construct transformative knowledge, which is knowledge that is underpinned by critical consciousness and that unmasks issues of domination and subordination, thereby challenging the status quo (Anderson, 2000). Such knowledge is constructed via the centering of voices that are often marginalized in relation to dominant perspectives (Anderson). AE, which similarly calls for knowledge that challenges the domination of Eurocentric perspectives (Marker, 2006), provides the mechanism for First Nations voices, knowledges and perspectives to be authentically present.

Some Aboriginal scholars have critiqued post-colonial theories, and others have critiqued feminist theories. For example Tuhiwai Smith (1999) argues that “post-colonialism is viewed as the convenient invention of Western intellects which reinscribes their power to define the world” (p. 14), and Marker (2004, 2006) notes that historically, post-colonial perspectives often dominated or obscured Aboriginal perspectives. These and other scholars argue against defining Aboriginal peoples solely in terms of colonialism, and against a perpetuation of the false notion that colonialism is a thing of the past. Despite such critiques, some indigenous scholars have described the value of post-colonial perspectives in providing tools for understanding the complexities of colonization (e.g. Duran & Duran, 1995) and for non-Aboriginal scholars to critically examine the influence of colonial discourses in their work (LaRocque, 1996). Indigenous and non-indigenous scholars have noted the advantage and necessity of cross-fertilizing knowledges (e.g. Harding, 2006), in this case Aboriginal and academic or Western/European knowledges (e.g. Barnhardt & Kawagley, 2005; Urion, 1999). In this study, interpretations of PCF and AE were stitched together to form a comprehensive web of relations (Cajete, 2000) that fits well with the concept of *Two-eyed seeing,* a phrase coined by Mi’kmaq elder Albert Marshall, where *scientific* knowledge is integrated with *traditional* knowledge in order to produce more complete understanding (Canadian Aboriginal Science and Technology Society, 2005). Two-eyed seeing was a guiding metaphor for this research, providing powerful symbolism since, literally, two eyes are critical for depth perception and accurate vision.

In this research, PCF was the lens of one of the eyes. PCF theorizing brings together post-colonial theories and feminist theories to form an understanding of how processes of marginalization and inequities along axes such as race[20] and gender are intersecting and synergistic in their effects. In doing so, PCF addressed the critique that either one of these theories (post-colonialism or feminism) alone ignores other significant axes of domination/oppression (Browne, Smye, & Varcoe, 2007). The lens of PCF allowed interpretations flowing from this research to be inclusive of historical relations and gender analysis. The particular interpretation of PCF employed in this research underscores a need to begin with the everyday experiences of people and connect these experiences to intersecting axes of power, such as race, gender, social status, and historical location, which are operational in society (Anderson, 2006). Because PCF draws attention to the often invisible discourses and the resulting societal structures that shape our everyday experiences, social processes that are taken for granted can be unmasked and, in doing so, "dominant discourses in healthcare and the politics of gender, race and class relations" can be challenged (Anderson & Reimer-Kirkham, 1998, p. 257). The lens of cultural safety is grounded in PCF perspectives and discourses (Smye, Rameka, & Willis, 2006). In particular, cultural safety draws attention to the ways in which health professionals understand and apply concepts of culture and power in healthcare practices. PCF fits well with decolonizing methodology because of its commitment to learning from subjugated voices, to transformative knowledge, and to social justice as an aim of research.

Aboriginal epistemology (AE) was the second lens for Two-eyed seeing. AE is generally defined as being inclusive of epistemological and ontological ideas (i.e. notions of knowledge are not neatly separated from notions about the nature of the universe). While AE represents a large body of diverse writings, ideas commonly included in writings about AE include: a) knowledge is underpinned by a world view/ontology of holism, constant cyclical motion and flux, interconnectedness and relational perspectives, sustainability, and deference to community versus individual perspectives (Battiste, 2000; Cajete, 2000; Little Bear, 2000); b) conceptualizations of health include living life in balance, physical, mental, emotional, and spiritual aspects of person, and a situation where the community and the nation are in harmony (Bartlett, 2005; Tuhiwai Smith, 1999); c) knowledge may be obtained via religious ceremony, visions, and spiritual experiences, and is passed on through the use of methods such as storytelling, traditional teachings, respect of ancestors, oral histories, and talking circles (Moore, 1998; Tuhiwai Smith); and d) the pursuit of knowledge for knowledge's sake alone is rarely sufficient; important knowledge is knowledge about relationships among all the entities of nature, especially the land (Marker, 2004; Richmond et al., 2005). In this study, the tenets of AE were defined, described, and implemented by the use of participatory methods, specifically, by the construction of and continued consultation with a Community Advisory Committee, including a community-based partner (elder/mentor) and the full engagement of three community-based research assistants.

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[20] I mark the term "race" with italics to underscore the contested nature of this word. Although the notion of distinct races has been debunked by science (Fee, 2006), it continues to be used to suggest that distinct genetic patterns are responsible for creating discrete groups of humans that are generally identified by a unique collection of physical characteristics.

The use of Two-eyed seeing added complexity to the study. It also added richness and resulted in the creation of knowledge that is less partial than would be the case if either of these perspectives were used alone (Barnhardt & Kawagley, 2005). The use of two perspectives allowed an opportunity to make visible the confluences and discrepancies between the perspectives, including a reflection on the differences between Eurocentric and indigenous knowledge (Battiste, 2008), and provided a pathway for a bridge of understanding between the two.

Methodological Approach

I situate this work in the genre of decolonizing methodologies (Bartlett et al., 2007; Tuhiwai Smith, 1999, 2006). Decolonizing research is research that has an explicit agenda to privilege indigenous perspectives while contributing to an emancipatory agenda linked with self-determination and social justice. It is commonly associated with non-exploitive, empowering, and productive methods (Laenui, 2000). The phrase *decolonizing methodology* was made popular by Tuhiwai Smith (1999) who writes about the need for indigenous peoples to take back the “research on Aboriginal peoples’ enterprise” so that knowledge that works for Aboriginal peoples can be constructed, and to reverse the potential for research to further marginalize and disadvantage Aboriginal peoples. Tuhiwai Smith argues that decolonizing methodologies are the means to achieve a research agenda that includes healing, transformation, and mobilization towards the goal of social justice. Such methodologies are steeped in indigenous processes (e.g. worldviews and approaches to knowledge acquisition), and ensure that the first beneficiaries are the indigenous people involved. Processes are just as important as outcomes in terms of the ultimate goodness of the research.

Research Design

The design used for this research was a community-based participatory qualitative study that drew on ethnographic methods and employed decolonizing methodologies. The ethnographic method of immersion facilitated my ability to draw on the expertise of First Nations community members to inform all aspects of the research project and thus fulfill my desire for this research to include and privilege perspectives that were grounded in participants’ experiences. I drew on an a priori assumption that research and science are not value-free and thus relations of power must be taken into account (Fletcher, 2003). In addition, prolonged exposure to the context of community facilitated my understandings of the community participants' life context and hence, their experiences (Carspecken, 1996). This allowed me to begin from a standpoint of understanding the everyday experiences of the community members whom I interviewed. As argued by Smith (1992), key insights about marginalized populations are achieved by starting from their experiences and linking these experiences with wider historical/social relations and power structures. My exploration of social/historical relations and power structures included an examination of arthritis health services.

This research had two research fields. The first field was an urban First Nations community with whom I partnered. My immersion in this context spanned three years (2006–2009). The second field included arthritis health services that could be accessed by the First Nations community members. Together, these two fields enabled data to be collected from a variety of perspectives.

Practices and Protocols that Shaped the Design

The design of this research was shaped by several Canadian research guidelines, which recommend appropriate research practices and protocols for research with Aboriginal peoples. The guideline that was perhaps the most influential in this work is *The 4Rs (Respect, Relevance, Reciprocity, Responsibility) of Aboriginal Health Research* (Archibald, Jovel, McCormick, Vedan & Thira, 2006). The principle of respect shaped my activities within the community. I explicitly sought out and valued the perspectives of community members. The principle of relevance was reflected in my actions that ensured the community had significant input into the research. Similarly, I showed responsibility in the research process by actively and continually engaging the community. However, it was perhaps the concept of reciprocity that most compelled my actions. Being acutely aware of my place as an outsider, and also the significant benefit I was deriving from the research (i.e. enormous amounts of learning and increased professional status related to obtaining an academic degree), I continuously strove to find ways of *giving back* to the community. My attempts at reciprocity included: 1) volunteering my time for community events, 2) providing tangible and intangible support to community members active in the research process (i.e. providing transportation since I have a car and many community members do not, and visits and phone calls, especially to elders[21]), 3) ensuring that those who participated in the research felt that their time and energy were valued (e.g. in providing meals and other tokens of appreciation), and 4) creating a health tool for distribution to community members (see knowledge translation activities below). My commitment to employ decolonizing methodologies and to ensure the community benefited from the research processes allowed the research to be consistent with *The 4Rs of Aboriginal Health Research*.

Another guideline that structured this work is the *Guidelines for Health Research Involving Aboriginal Peoples* developed by the Canadian Institutes of Health Research (CIHR, 2008). These guidelines attend to the principles of *Ownership, Control, Access, and Possession*[22], known as the OCAP principles (FNC, 2007; Schnarch, 2004). A key point underscored by these guidelines is the need for *community consent* for the research. The notion of community consent is embedded within the rights of Aboriginal peoples to be self-determining and self-governed and also in many Aboriginal worldviews that foreground community over individual perspectives. While the notion of community consent is clear, how to obtain such consent is not, given the complex networks of political and traditional authority that permeate many First Nations communities. In this study, community consent was obtained via approval through Chief and Council, and oversight of the project was designated to the elders via a Community Advisory Committee (CAC) comprised mainly of elders. Ongoing community consent was evidenced by continued participation of community members in the CAC, which met regularly throughout the study and provided essential guidance. Another component of the guidelines that was observed was the principle of *increasing community capacity for research*. Three research assistants were hired and they, as well as members of the CAC, participated in research training and a multitude of research activities. While this contributed to capacity building within the community, I acknowledge that capacity building is reciprocal in that I experienced significant learning as a result of this research. In general, other principles in these guidelines overlap with the principles discussed above.

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[21] I use the term elders in keeping with the way it is used in this community; elder is the designation applied on the basis of age. Hence, in this paper, elder refers to community members who are over the age of 60 (junior elder is a title give at age 55). This is in contrast to the way the term is defined in other contexts. For instance, the designation of elder is sometimes based on characteristics such as leadership within the community (e.g. Barnhardt & Kawagley, 2005). In these later cases, the specific meaning of the term elder is often indicated by capitalizing the first letter (e.g. Elder).

[22] The history of research with Aboriginal peoples includes multiple examples where the data (sometimes in the form of genetic material or traditional knowledge) were controlled solely by researchers, leaving Aboriginal peoples unable to reclaim data that was seen as valuable, nor influence how the data were used. In response, the OCAP principles, which advocate for Aboriginal ownership, control, access, and possession of all information collected or generated during the research process when Aboriginal peoples are the subject of the research, were formulated (FNC, 2007).

Research Activities in the Community Field

The *Arthritis Project*, as it came to be known in the First Nations community, was designed and implemented in collaboration with community members (i.e. the CAC and the research assistants). Research activities included hundreds of hours of immersion over a three-year period[23], as well as in-depth, open-ended interviews with 24 community members about their experiences with arthritis. My understandings of the data generated in this field were heavily influenced by extensive dialogue with the research assistants, who were community members.

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[23] Immersion in the community was enabled by the fact that I live adjacent to the community.

Community Setting

The research field was a small First Nations reserve community (population approximately 450 people, less than 300 of whom lived on reserve lands) situated in the suburbs of a large metropolitan area in British Columbia. Health services, including primary, secondary, and tertiary level of services, were available within a relatively close proximity (i.e. within two to 15 km). As such, few health services were available on reserve[24]. However, the Nation had a daycare, a small school, a small convenience store, and a large community centre/gym. The Nation was politically and economically active. For instance, the Nation developed reserve lands through business ventures for economic gain. Political activity towards self-government included the passing of a land code that allowed independent control of reserve lands and the development of a structure that promoted their consultation on economic and other activities occurring within their traditional territories. Despite these economic and political gains, many community members experienced hardships that were related to the colonial past. For instance, unemployment and poverty were widespread; educational achievement and substance use among the youth continued to be points of concern for the community. Hence, the context of community life included both positive and negative experiences for community participants. These experiences are discussed in more detail, in relation to the central questions of this dissertation, in the findings chapters.

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[24] Health services available on reserve included CHR services (medical transportation, help with negotiating NIHB, homecare), home support, and part-time nursing services for activities such as nutrition counseling, footcare, education and illness support.

Gaining Community Access

Gaining access to the community involved an extended timeframe. Initially, my inquiries with the community as a potential site for partnership research met with some resistance. I was told by the person I first contacted “we don’t do research with outsiders,” reflecting the uneasy relationship some community members have with outsiders. Eventually, once I used the correct channels of inquiry within the community, I developed a strong working relationship with the community’s health leader, which included extensive face-to-face dialogue. Through this relationship I was able to understand the community’s expectations for research.

The health leader facilitated my entry into the community, including approval of the research partnership by Chief and Council. During the first year of my immersion in the community, I spent time with the health leader to discuss the community’s needs and perspectives around the research. In addition, she invited me to participate in staff development activities planned for all staff members who worked in the community’s health and social development departments. I participated in three multiday workshops on issues around trust, truthfulness, and self-insight as a means to become known in the community and to begin understanding community dynamics. Further, since oversight for the research had been delegated to the elder’s group, via a CAC that would be composed mostly of elders, the health leader connected me with the elders’ coordinator who facilitated my volunteering at elders’ and community activities. For example, I took notes at elders’ meetings and worked at concession stands during community events. During the first year, which was prior to the official sanctioning of the research by the Nation, my goals were to become known and to demonstrate my commitment to the community by being useful. This preliminary year allowed me to form a network of community members who were interested in the goals of the study and the work that would be needed to accomplish these goals.

Participatory Processes in the Community

As mentioned earlier, a Community Advisory Committee (CAC) was constructed to provide guidance for the project. The key role of the CAC was to ensure that the project unfolded in ways that were appropriate and respectful, as defined by them, and, would result in findings that were useful to the community. Initially, because elders were to be key members of the CAC, I engaged the elders' group (about ten elders participated) in a discussion about the potential research, arthritis, and the health system. After this discussion, one elder volunteered to be the primary community partner for the research. She played a central role as my partner and mentor during the entire research project. Other elders were recruited, via a personal invitation from me, to be a part of the CAC. On the CAC were five elders, a liaison for First Nations Inuit Health (FNIH; the federal body responsible for on reserve health services), the elders' coordinator, and a representative of the community-at-large, since we recognized that arthritis was not just an issue for elders. Over time, the composition of the CAC changed as people left jobs and one elder died, however, elders always constituted the majority of members.

The CAC was particularly active in determining the plan for how the project would unfold. We (CAC) met monthly over a period of about a year. Meetings were always held in the community, they were always co-chaired by the community partner and myself, they always began with a prayer, and meals were always served. While we did discuss research topics, like the complexity of OCAP principles, we also discussed what was currently happening in the community. Thus, the research always interfaced with community realities. Meetings tended to be long to allow plenty of time for discussion, reflection, and decision-making. These meetings were invaluable in relationship building, in understanding the rhythms and issues of the community, in situating the research within the community context, and in the development of an effective plan for the project.

One of the first tasks of the CAC was to help construct a Letter of Agreement to conduct research within the community (see Appendix A). This letter underscored the research processes that were based on the *Four Rs of Aboriginal Health Research*. In keeping with the OCAP principle of *community control of data*, the letter identified that each community member who participated would be the owner of their own data. The community partner and I presented the letter to Chief and Council where it was approved.

As the CAC constructed a plan for the project, one critical decision made was to reconceptualize the term arthritis. The CAC elders felt that the term may not resonate with all community members who were exposed to recruitment materials or involved in interviews. They also felt that some members may not know that they have arthritis, since many in the community avoided contact with doctors. The CAC recommended that the phrase *aches and pains* be used instead of the word arthritis in the interactions with participants and potential participants. However, the informal community title of the research, The Arthritis Project, persisted through the research process.

A key part of the project plan was to hire research assistants from the community (CRAs) to be involved in data collection and interpretation, and knowledge translation. As the CAC discussed this part of the plan, we grappled with the concept of *community*. It was noted that not everyone on the official Band roster lived and/or participated in community activities, and conversely, others who were not on the roster regularly visited, participated, or lived in the community. Members of the CAC defined community in different ways, many of which did not conform to either the official roster or the boundaries of reserve lands. In the end, the CAC decided to use a broad interpretation of the term community, initially to ensure a broad pool of applicants for the position of CRA, and later to help reflect the varied perspectives of community held by community members.

Although the plan had been to hire one CRA, in the end three were hired. None of the eight applicants for the position had all the required skills, yet together, the three women who were hired had a comprehensive skill set. Although all were or had been single mothers, they were of varied ages and had varied ties with the community. Over time, the four of us formed a tight bond and functioned well as a data collection and analysis team.

Data Collection in the Community

In preparation for data collection in the community, a team and research skills building workshop was arranged for the CAC and the CRAs. The workshop was led by an Aboriginal scholar hired for this purpose. This workshop grounded us all in methodologies that are steeped in AE, and led to some modifications of research processes and protocols. For instance, the interview guide was altered to be more relevant to the community context (see Appendix B). CRAs were also coached to bring themselves and their histories with community members to the interview, rather than assuming the role of an *objective* observer. During this training, the ethical complexities of conducting community-based research were explored such as the challenges to maintaining confidentiality and privacy for participants. In particular, CRAs engaged in role playing to allow practice in working through ethically complex situations. This training brought us together as a solid research team, capable of enacting community-relevant research.

Recruitment efforts for data collection were aimed at any adult community member who had ongoing and longstanding[25] musculoskeletal pain that interfered with activities of daily living. Purposeful and snowball sampling were used. Recruitment flyers were posted in community public areas and delivered door-to-door. To begin with, the CRAs generated a list of potential participants based on who probably had stories they were willing to share. Other potential participants were identified based on suggestions from community members who were interviewed. In many cases, the CRAs engaged potential participants in dialogue to ascertain their interest in the study. In the cases where the potential participants were elders, the elders' coordinator, acting as a liaison between the researchers and the elders, introduced the study and determined their interest. I met with all potential participants who expressed interest to explain the study and obtain informed, written consent (I read the entire consent from to participants) if they agreed to participate (see consent forms Appendix C). While the CRAs and I worried that community members might feel obliged to participate, the fact that some members declined to participate (three elder men, one elder woman, one middle-aged woman[26]) indicated that most felt comfortable making a decision to participate or not[27]. Only two participants self-referred while all others were purposefully invited to participate.

The CRAs and members of the CAC were also invited to participate. Including the CRAs and the CAC members in interviews allowed them to be participants in their own inquiry; they identified potential participants and became participants themselves, reflecting authentic CBPR (Fletcher, 2003) and “indigenous research methodologies…that enable and permit Indigenous researchers to be who they are while engaged actively as participants in research processes that create new knowledge and transform who they are… (Weber-Pillwax, 2001, p. 174). While this approach can be considered *messy* in that it can imply a lack of objectivity (Ferguson & Thomas-Maclean, 2009), it allowed “participants to own the process…arguably in ways that traditional, scientific research methods cannot” (p. 9).

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[25] The CAC suggested that longstanding be interpreted to mean at least one year.

[26] People who declined most commonly reported that they were not comfortable or "ready" to talk about their pain. Most declined at initial contact, however, one woman declined after she read the interview guide.

[27] The topic of recruitment practices was given considerable attention during community-based dialogue sessions given the lack of an intermediary person in the recruitment of potential participants who were not elders (n = 15). A number of factors suggest that participants were comfortable in their decision to participate. For instance, community members who were known to be willing to share personal pain stories were purposefully approached. In addition, there was always a delay of at least one day each of the steps: initial contact, meeting to sign consent, and interview meeting, allowing participants time and opportunities to reconsider willingness to participant. Finally, the CRAs did not hold positions of power within the community and hence, there were no identified negative repercussions for community members who refused to participate.

Once a community member agreed to participate, an interview was arranged and consent was reaffirmed at the time of the interview. In most cases, I interviewed with a CRA (joint interview), unless the participant specifically requested otherwise. One particular CRA and I did the bulk of the joint interviews (12/14 joint interviews). The interviews that were conducted by a sole interviewer were conducted by myself (4) or by a CRA (6) alone. Most interviews were conducted in the community elders’ lounge, however community members were also interviewed in their homes or in other private locations as per their requests. Interviews tended to be at least an hour in length; a few lasted several hours. Out of respect for community members who had a story they wished to share, we continued to conduct interviews until everyone interested had a chance to participate despite the fact that common themes were apparent after about 20 interviews.**The community participants.** In all, 24 community members were interviewed (see Table 1), including three CRAs and two members of the CAC. Sixteen participants were women and eight were men, roughly reflecting the reported gender distribution of arthritis. While most participants (58%) reported that they had, in the past, been told (by a physician) that they had OA, three participants had been told they had RA and two had been told they had FM (or a FM-like condition); five participants had never sought and/or received a diagnosis of arthritis. Participants were mostly employed (62%) although two reported being unemployed and four reported they received disability pensions. However, only four, out of the 20 participants who responded, reported that their finances were adequate to manage their health. Most participants lived with nuclear or extended families; only four participants reported living alone.

Table 1

Number of First Nations (N = 24) Participants by Gender and Age Range

Participant gender and age range	**Number of participants**
Women aged 33–54	8
Women aged 55–64	4
Women aged 65–78	4
Total women	**16**
Men aged 42–54	7
Men aged 55–64	1
Men aged over 65	0
Total men	**8**

Fieldnotes from immersion experiences. In addition to interview data, community-based data included extensive and detailed fieldnotes written by me regarding my immersion experiences, which included my participation in a variety of community events (e.g. sports, cultural and family events), as well as day-to-day experiences while on the reserve. My exposure within the community was facilitated by the Arthritis Project office, which was provided to me for one year. Since this office was located adjacent to the reception area in the main Band office, which many community members accessed for support, this office enabled community members to engage with the project. The project office door was consistently open, facilitating a fairly regular stream of visitors (elders, Band employees, and the Chief) who stopped by for conversation. In addition to enhancing my understanding of the community and the visibility of the project in the community, the office allowed the work of the CRAs to be visible within the community. In general, my fieldnotes included both a descriptive component (answering the questions Where, Who, What, When and How) and an analytical component (including personal reflections and methodological notes). See Data Analysis below for more details.

Research Activities in the Arthritis Services Field

Research activities in the arthritis services field included partnership and immersion in the specialty (secondary and tertiary) healthcare structures that have been set up for people with arthritis who live in the region within which the First Nations community is located. These are services that community members could (and in some cases did) access for specialized care of arthritis. My immersion in the field of arthritis services, captured in detailed fieldnotes, included approximately 100 hours of dialogue with, and observation of, arthritis researchers, administrators, and practitioners. Other data were generated by open-ended interviews with healthcare professionals who provided specialized arthritis care. The analysis of these data enabled an understanding of arthritis services, in particular an examination of how services were aligned with First Nations peoples' experiences of arthritis.

Three healthcare settings (one main and two ancillary) comprised this research field. The main setting for immersion and interviews was the arthritis centre that provided tertiary level (provincial) arthritis services, primarily outpatient and outreach services, as well as regional health professional development activities. This centre was a teaching hospital and the hub of arthritis activities within the region. It was also home to arthritis research organizations. The ancillary settings were affiliated with the centre. One ancillary setting was a tertiary level inpatient rehabilitation setting for people with arthritis; the other was a community hospital-based arthritis outpatient program located in the same suburb as the First Nations community. Together these settings provided the secondary and tertiary level of arthritis healthcare that could have potentially been accessed by community participants (most services required referral from a rheumatologist). Primary care settings were not included in the scope of this study since they are not typically focused specifically on arthritis care.

Gaining Access

Access to the arthritis services field was facilitated by my familiarity, as an experienced nurse, with the acute care health system. In addition, I had served as a clinical nurse specialist on an inpatient unit that was affiliated with one of the ancillary settings. Consistent with a participatory approach, I developed a working partnership with a healthcare provider from the arthritis centre who engaged with me throughout the study, providing feedback on study protocols (including methodological and analytical perspectives) and facilitating immersion and recruitment opportunities. Since arthritis services in First Nations communities were part of this healthcare provider’s portfolio, he had a keen interest in this study and was an active partner. In the ancillary settings, I established relationships with managers who facilitated recruitment of healthcare professionals (HCPs) for interview. In general, HCPs from all settings were concerned about arthritis in Aboriginal peoples and interested in providing support for the study.

Data Collection

Data collected in this field included a) open-ended interviews with HCPs (N = 30) and, b) extensive detailed fieldnotes from immersion activities. Immersion activities, which unfolded over the course of three years, included my participation in professional development activities for HCPs providing arthritis care, some of which occurred weekly while others were annual or ad hoc events. On several occasions, especially when the topic was arthritis in Aboriginal populations, I was asked to lead or co-lead professional development activities. For instance, my healthcare provider partner and I were asked to lead a special education session on this topic at the tertiary inpatient setting. In addition, I was invited to participate in the centre's service development initiatives around arthritis services for Aboriginal peoples. This included meetings with nurses providing services in First Nations communities and meetings with researchers. A key immersion experience, which occurred towards the end of the study (fall, 2009), was my participation in an international research symposium on rheumatic diseases in Aboriginal populations, which I attended as part of the group of researchers from the arthritis centre. Since this symposium brought together experts and consumers, it provided an invaluable opportunity to examine dominant conceptualizations in arthritis care and how priorities for arthritis service delivery and research are discussed. My immersion in the arthritis services field allowed me a window through which to examine these services in relation to the data collected in the community field.

Interviews were conducted with HCPs who provided specialty arthritis care in this field. I conducted in-depth individual and group open-ended interviews with 30 HCPs to discuss their experiences of providing care to Aboriginal patients and their perspectives about service delivery in relation to this population. Recruitment was facilitated by my healthcare partner who sent emails to most of the healthcare professionals working at the centre, inviting HCPs to contact me if they were interested in participating. He also arranged for me to introduce the study at staff meetings in the centre. Managers in the ancillary settings also arranged opportunities for me to introduce the study to staff at staff meetings. In addition, flyers were posted in public areas of the settings. My opportunity to present ongoing education to HCPs, on the topic of arthritis in Aboriginal peoples, provided considerable visibility for the study. While several HCP contacted me to be interviewed, because of the high workloads in the healthcare context, managers suggested and organized group interviews on two occasions, where 13 of the 30 HCPs were interviewed. In most cases, interviews were conducted in the workplace of the participant and included approximately one hour of discussion and dialogue. The two group interviews were conducted in the respective staff meeting areas of two of the arthritis field sites and discussions lasted approximately 1.5 hours.

Healthcare provider participants. Twenty-eight of the HCP participants were associated with one or more of the arthritis services settings, and two HCPs were employees of the First Nations community. Most were women, although three men were interviewed. Almost all HCP participants were experienced arthritis practitioners, only four had fewer than five years of experience working in their current position. See Table 2 for a breakdown of HCP participants by discipline.

Table 2

Number and Type of Healthcare Professionals Interviewed (N = 30)

Profession	**Number interviewed**
Nurse (RN)	6
Rheumatologist	5
Social worker	1
Community health worker	1
Manager	1
Physiotherapist	4
Occupational therapist	12

Data Analysis

Data to be analyzed from each study field included interview data (from community participants and HCP) and fieldnotes from immersion experiences. Analysis occurred concurrently with data collection in an iterative manner (with early analysis shaping data collection and vice versa). An interpretive thematic approach to analysis was used (Sandelowski, 1995; Thorne, 2000; Thorne, Reimer-Kirkham, & O'Flynn-Magee, 2004) whereby data were systematically discussed and rediscussed, or read and reread, to detect meanings and thematic categorizations, contradictions, and inconsistencies, and to "generate conclusions about what is happening and why" (Thorne, p. 69). This interpretive approach was informed by PCF and AE; for instance, as community-based data were (re)read and (re)discussed, I paid close attention to the indigenous narrative, especially as it described "economic and cultural conditions" (Marker, 2003, p. 363), and could articulate some of the "root causes of social inequities" (Reimer-

Kirkham & Anderson, 2010, p. 197). An indigenous lens was privileged in the analytic processes, through extensive dialogue with the CRAs, particularly in comprehending and synthesizing the community-based data (Marker). The CRAs and I met weekly, often for three hours or more, to discuss emerging understandings and to interpret our research experiences. The overall goal of the analysis was to have it grounded in participants' stories of their everyday experiences (Reimer-Kirkham & Anderson, 2002).

Interview Data

Interview data was in the form of transcriptions from audio-recordings. In the process of managing the transcript data, information that could potentially identify participants was removed. Interview data from the community participants and healthcare professionals were analyzed as separate data sets but similar processes were used to organize, code and interpret the data. Input from the CRAs, my healthcare partner, the CAC and my doctoral supervisory committee was obtained throughout the two-stage process of interview data analysis.

Stage one of the analysis involved establishing a coding framework and coding all transcripts line by line. Interviews were transcribed by a professional transcription service; transcripts were checked for accuracy by me and then uploaded in NVivo (a qualitative data analysis software package) for coding. As the first few transcripts from community participants became available, the CRAs and I coded them together and developed coding categories in a meaningful and consensual way. Differing interpretations were encouraged and explored in a reflexive manner, often pointing to areas for further consideration. The codes developed, for instance codes such as *seeking help from family and friends, social isolation, avoiding or delaying healthcare access*, and *obstacles to healthcare access,* closely reflected the data generated. These initial codes were refined, revised and added to as discussions unfolded and more transcripts became available.

Codes for HCP data were generated in a similar fashion; although my healthcare partner did not participate directly in the coding process, discussions that occurred approximately every other week offered an opportunity for me to share, discuss and receive feedback on emerging coding categories. In both data sets, exemplars that reflected commonly used codes, themes, and key concepts arising from stage one of the analysis were captured as memos within the NVivo software and constituted data that were considered for further analysis. Memos and beginning understandings were shared with the CAC and my doctoral supervisory committee for input and interpretation. These reflexive and interpretive discussions were key to data analysis and underpinned stage two of the analysis process.

In stage two of the process, coding categories, themes, concepts, and exemplars were brought to a higher conceptual level, one that was broader and more theoretical in nature. For instance, theoretical ideas, such as social suffering and racialization, were linked with coding categories. The theoretical ideas were shared with the CRAs and the healthcare partner for their critical consideration (Thorne, McCormick, & Carty, 1997); their insights and feedback were incorporated to accomplish a “mutual negotiation of meaning” (Lather, 1991, p. 57) and to enhance the descriptive and interpretive validity of the findings (Lather). The goal to establish a reciprocal dialectic process between the data, my initial interpretations, and participants’ perspectives reflected in the data, was reached. As can be expected, differences in understandings and interpretations were offered by the various individuals involved. However, differences were seen as adding to the richness of the analysis and were incorporated and discussed as part of the overall analysis. The second stage brought the analysis to a higher conceptual level as theoretical insights were generated and compared with existing knowledge.

Analyzing Fieldnotes

My fieldnotes captured the details of my immersion experiences in the community and in the healthcare settings, my responses to the experiences, and my analysis of social processes that might be shaping those experiences. For example, my fieldnotes from my first inquiry with a community member (discussed above under the subheading Gaining Community Access) document my surprise and disappointment with the community member's feedback to me: "we don't do research with outsiders." They also explain my analysis of this feedback as a marker of community resistance to outsiders and also as a probable product of historical incidences. Hence, the process of writing fieldnotes was itself an analytical process (Emerson, Fretz, & Shaw, 1995). Analysis of the fieldnotes constituted reading and rereading them, and reflecting on both the experiences and the fieldnotes over time, as my understandings emerged. Reflections were facilitated by discussions with participants, partners, CRAs, and members of the CAC and my doctoral supervisory committee. Typically, the writing of fieldnotes, and the reading of and reflecting on them, resulted in a thematic interpretation that was captured as a memo in the NVivo software and used to inform the ongoing analysis of interview data. The outcome of the data analysis was a synthesized account of the complex interrelations (Anderson, 2000) shaping people's experiences with arthritis, and also the organization and delivery of arthritis services.

Establishing Rigor in the Research Process

Substantial debate exists within the literature about what marks *good* qualitative research (Lincoln, 1995). Indeed, because the researcher is the tool for data collection and analysis, the findings are socially constructed. Therefore, markers of rigor have to do with the nature of the relationships with participants and the process of interpretation, as well as the trustworthiness of the results (Cutcliffe & McKenna, 2003; Tobin & Begley, 2004). Scholars writing from the perspectives of PCF and AE have further defined key elements of the research process necessary for quality work in these genres. For example, both perspectives demand attention to these three markers and also to the *praxis* nature of the work. Praxis, in this context, denotes a commitment to a social justice/change agenda (Reimer-Kirkham & Anderson, 2002, 2010) and to contributing to the self-determination of Aboriginal participants (Tuhiwai Smith, 1999). I attended to praxis by aiming for knowledge that would be useful to First Nations peoples in general and, in particular, to the First Nations participants of this study, and also by aiming for knowledge that would provide a foundation for a change in the healthcare system.

The Nature of Research Relationships: Reflexivity and Positionality

A significant technique that I employed throughout this study was a reflexive analysis of positionality and power relations. Since hearing subjugated voices was a goal in this research, "careful attention to the social and historical positionings of the researcher vis-à-vis research participants…is paramount" (Reimer-Kirkham & Anderson, 2002, p. 10). I followed AE scholars' recommendations for researchers, especially for non-Aboriginal researchers, to engage in a pointed reflection and a "critical examination of how their sources of family, class, and ethnic privilege intersect with the historic circumstances of Indian people" (Marker, 2004, p. 477). My reflection revealed shifting power dynamics. For instance, in community research meetings, my position as a middle-class nurse researcher of Euro-Canadian descent sometimes placed me in a position to influence the outcomes of methodology/method-related discussions. I was actively cognizant of and concerned about my potential power in these situations. My commitment to decolonizing methodologies, including my reliance on the guidance of the CAC and the CRAs, helped ensure that participants had the power needed to ensure that the research unfolded in a way that was respectful and acceptable.

In the arthritis services field, I positioned myself as a healthcare professional that was new to the specialty area of arthritis. This junior positioning was used to diffuse the power of surveillance and evaluation that researchers are often seen to have and that can make potential research participants wary of participation in the research. However, there were times when the power dynamics among healthcare professionals meant that I had little power in a research encounter, particularly as a nurse speaking with physicians who were specialists. Regardless of the particular power dynamic that unfolded in any given research encounter, issues of respect, reciprocity, connection, and personal awareness were foregrounded in all research relationships (Marker, 2004).

Reflexivity about Processes of Interpretation

I followed PCF scholars' direction that the researcher examines, through reflexive critique, the nature of the research processes and the researcher's influence on them (Reimer-Kirkham & Anderson, 2002). For instance, I reflected on how my position as a Euro-Canadian, middle-class nurse interested in social justice for Aboriginal peoples in Canada influenced the research processes. In addition, because interviews in the community setting were conducted by different people (CRAs and myself), I engaged the CRAs in dialogue about the influence of the interviewer on the data. In some cases, CRAs compared what they knew of the participant with what the participant had said in the interview to help us better understand the nature and limitations of the data. For instance, a CRA noted that one participant had been extremely reluctant to criticize her physician, or any aspect of the health system, on tape, as opposed to a multitude of discussions the CRA had had with this same participant in the past. This discussion, and others like it, allowed me to understand the degree to which interview data is constructed by contextual factors.

My reflexive processing about my positionality and influence was captured in journal notes that were written throughout the research process. I read and reread these notes as a reminder of my own power within the process, as well as the power of contextual factors to shape the data and the interpretation of the data.

Trustworthiness of the Findings

Given that research findings do not result in absolute truths and findings generated reflect specific historical, social, and political contexts (Harding, 2004; Thorne et al., 2004), researchers are challenged to ensure that research findings are credible and relevant interpretations of participants' experiences. The credibility and relevance of the findings were demonstrated by the responses of community members during the final Arthritis Project feast held for community members. Responses from community members who attended this dinner indicated that the findings resonated with their experiences. In addition, as noted earlier, unfolding interpretations were repeatedly discussed with the CRAs and research (community and arthritis services) partners. My analysis resonated with the CRAs, community members and HCPs; these responses provided some validation of the interpretations found in this dissertation.

Other ways of ensuring rigor in qualitative data analysis were also employed. For example, triangulation of data was accomplished because of the multiple sources of data, including fieldnotes from my immersion, interview data, and feedback from partners and participants. In addition, prolonged engagement in the fields helped to ensure that I was exposed to the varied rhythms of the settings over time. In analyzing the data, I took particular notice of case examples that did not seem to fit the pattern of most other cases. This negative case analysis (Bowen, 2008) allowed the complexity of the data to be understood. Perhaps the most important tool that I used was extensive member-checking over the course of the project, as detailed above, which provided abundant opportunities to clarify and deepen my understandings through discussions.

Knowledge Translation Activities

Knowledge translation (KT) is ongoing and continues into the present. KT was prioritized in the community because of the specific obligation of this research towards the community. There were three KT activities in the community. The first was the construction of a final report for participants (see Appendix D), which was presented and discussed at a final community feast. This event contributed to the usefulness of the research by broadening participants' understanding of their arthritis and in doing so, created a potential for new understandings to generate new opportunities for empowerment (Fletcher, 2003; Smylie, 2005). The second was the development of a Health Handbook, for use by community members, to facilitate communication between community members and HCPs. Each participant received a copy of the handbook and it was also made available to the community health department. This tool offered opportunities for empowerment in community members because it provided a means by which community members could gain some power and control in healthcare encounters. The third activity was to create a final report for Chief and Council. This report offered a multitude of suggestions that the community could use to: 1) enhance the chronic illness care of community members (i.e. standard use of the handbook with community members who have chronic illnesses), 2) improve the community health services for community members with chronic pain/arthritis, and 3) enhance advocacy efforts with Health Canada (for instance, regarding NIHB and housing policies). These KT activities helped ensure my attention to the issues of praxis.

KT activities in the arthritis services field are ongoing. Meetings have been held with my healthcare partner and his supervisor. They both have a keen interest in engaging with the findings as they continue to develop specific arthritis services for Aboriginal populations, and I have been invited to continue to participate in these service development activities. Part of the KT plan is to engage HCP groups who provide arthritis services in discussions about the findings and implications for practice. These kinds of discussions have good potential to enhance HCPs' understanding of the sociohistorical context of patients' arthritis experiences (see Chapter Seven). My continued engagement with arthritis services leaders will provide ongoing opportunities to integrate the critical social knowledge emerging from this study with the biomedical knowledge that is predominant in the arthritis services settings (e.g. Anderson et al., 2010).

Ethical Considerations

The primary ethical imperative that is foundational to this research is to "first do no harm" (Holkup, Tripp-Reimer, Salois, & Weinert, 2004). Institutional review boards typically provide the lens to establish that potential research is positioned to do no harm. In this study, this type of ethical approval was obtained via institutional review from the healthcare sites that deliver specialty arthritis services and from the UBC ethics board. In keeping with ethical guidelines that are specific to Aboriginal peoples (see above), community approval for the research was also obtained through the community's Chief and Council. Participants were protected through these reviews, as well as by obtaining informed consent and reaffirming participant consent with each new interaction.

An important consideration with respect to the safety and well-being of community participants was the plan that was developed, during early deliberations of the CAC, to ensure that participants were not harmed through discussions of their aches and pains. The CRAs were coached to be attuned to participants' affect during interviews. The plan included 1) having Kleenex® as part of the basic interviewing kit, and offering emotional support if participants became upset, 2) giving participants who became upset options of skipping questions or discontinuing the interview, 3) providing referrals to the community mental health counselor if participants approved, and 4) staying with the participant, as needed, until the episode resolved. While the purpose of interviews was not to uncover traumatic histories, interview questions did pose a potential to stir uncomfortable memories. Although a few participants did cry during the course of the interviews, no-one wished to skip questions, discontinue the interview, or be referred to the counselor. The CRAs and I were mindful in our attempts to create a safe environment that fostered the ability of participants to speak about issues that they were comfortable to discuss.

While formal processes were in place to help ensure the safety of participants, in this research I was also concerned with the safety of the CRAs. Since CRAs were embedded in the complex dynamics of the community and discussions included content around peoples' experiences of suffering, interview experiences were sometimes emotionally charged. In a few instances, the personal histories of the CRAs in the community contributed to their discomfort during some of the research processes. In one instance in particular, a CRA had not disclosed a previous discordant relationship with a participant whom we jointly interviewed. While this interview unfolded well and contributed to a renewed, positive relationship between the CRA and the participant, in the meantime anticipation of the interview had caused the CRA considerable stress. Being aware of the complex networks of relationships within the community, I specifically and repeatedly encouraged CRAs to consider their own needs for safety in determining who they would interview.

Limitations

The limitations of this study warrant consideration. First, the scope of this work, as a doctoral dissertation, required creating some boundaries around the number of research questions that could feasibly be addressed. For instance, although the intersections of gender and age were considered in relation to experiences of health and healthcare, the axis of colonialism remained the focus of analysis given the theoretical and methodological frameworks. Second, given that the CRAs were instrumental in creating the list of potential community participants, the sample must be acknowledged as reflecting the community as experienced by the CRAs. Because each CRA came from a different family within the community, the CRAs did reflect diverse components of the community. However, the extent to which this sample is a representative reflection of the community is not known. As such, generalizations from this work must be drawn with caution. Indeed, the degree to which this community reflects other First Nations communities is not fully known. However, the findings related to the socio-historical context of health and illness are congruent with available literature (e.g. see Adelson, 2005), and the community's profile is consistent with known statistics regarding the social determinants of health in Canadian reserve communities (e.g. Statistics Canada, 2008). These congruencies suggest that aspects of these findings will have relevance to the contexts of other First Nations communities in Canada.

Summary

The ethical obligations in doing this kind of work are considerable. These obligations are based on the history of research *on* Aboriginal populations and hence today's imperative is to avoid research that reinscribes colonial advantage and disadvantage, and the potential for Aboriginal peoples, including those who are hired as CRAs, to be made vulnerable by research processes. The design of this study, as community-based, participatory, and immersion-focused, helped ensure that ethical obligations were met. In addition, the lens of Two-eyed seeing and the extensive dialogue with community members helped position this work in the genre of decolonizing methodologies. Attention to praxis, the nature of research relationships, and methods of interpretation helped ensure the integrity of the findings and, indeed, the entire study. Reflexivity formed the foundation of this study and informed my understandings related to the findings of this research.

CHAPTER FOUR: PREAMBLE TO THE THREE FINDINGS CHAPTERS

The purpose of this chapter is to orient the reader to the following three findings chapters (chapters five, six, and seven) in relation to the research questions, the methodological perspectives and the two research fields. Consistent with the methodological perspectives of this study, in which Two-eyed seeing (enabled by the use of a post-colonial feminist lens and a lens based on Aboriginal epistemology) informed decolonizing methodologies, the findings chapters are organized to first discuss the experiences of community members with arthritis so that all further discussion is grounded in the experiences of those participants. The second findings chapter situates community participants' experiences, related to living with aches and pains and accessing the health system, within community norms and prior experiences, located in historical and social structures. Hence, the community-based data is discussed in these first two findings chapters. The third findings chapter, based on data collected in the health services field, considers the organization and delivery of arthritis health services and the ways in which these services have been shaped. Included in this final chapter is an analysis of how well these services are aligned with the experiences of First Nations peoples with arthritis. Such an analysis is permitted by considering the three findings chapters in relation to each other.

Overview of Chapter Five: "Why Do I Have So Much Pain?"

In response to the first research question (see page ten), the first findings chapter, entitled "Why Do I Have So Much Pain?" explores the experiences of arthritis as told by community members who participated in interviews. As noted earlier, the term arthritis was not used in recruitment of participants nor in interview questions. As recommended by the Community Advisory Committee, the term *aches and pains* was used instead. This change brings to question the meaning of the term arthritis in this community. Indeed, despite the fact that some community members favoured the term arthritis as an explanation for their aches and pains, community members' experiences of arthritis/aches and pains did not reflect a purely biomedical phenomenon. These findings indicate that biomedical labels, and the meanings they hold, can be used to both explain and/or obscure discussions of broader notions of suffering (Baum, Begin, Houweling, & Taylor, 2009).

In using aches and pains as a starting point and an interview guide that prompted storytelling, participants shared a plethora of powerful stories about how they understood their aches and pains. The use of a post-colonial feminist lens drew my attention to the historical, social, and economic context of peoples' lives that was revealed in these stories. Details of these contexts flowed readily during interviews, aided by the presence of research assistants in many interviews, who created safe spaces for discussions. Through almost all of the stories, a backdrop of social suffering was portrayed. Notwithstanding the magnitude of the hardships and suffering discussed, participants' stories also revealed their strength and agency. The telling of stories of strength has both a moral and a pragmatic purpose because it allows a more just, complex, and complete picture of peoples' experiences to be produced, while at the same time offering a starting point from which to build upon (Andersson, 2008). Despite my intent to portray a complex and complete picture, because the topic of this dissertation is tightly linked to pain and suffering, the balance of hardship stories in relation to stories demonstrating resilience and resistance is not quite equal. Particularly in this first findings chapter, stories of hardship and suffering take a prominent place as I answer part of the first research question for this dissertation: What are the health experiences of community participants with arthritis?

Overview of Chapter Six: "I've Just Learned How to Deal with It."

The second findings chapter is guided by the following research questions: What are the healthcare experiences of community participants with arthritis? and What shapes community members' utilization of arthritis health services? In order to understand community members' experiences and utilization of health services, it was necessary to first situate health services use within the broader context of *living well with aches and pains*. Hence, in this chapter I briefly discuss modes of living well, while spending the bulk of the chapter exploring health services use.

I begin this second findings chapter by discussing a strong community norm, labeled in this analysis *suffer in silence.* This reflected the theme of many of the participants' stories where suffering was normalized and silence was endorsed as the appropriate response. As per a decolonizing intent, I consider this norm and situate it within a colonial history (Tuhiwai Smith, 1999). Intersecting with the process of suffering in silence was community members' use of healthcare services. Most community participants reported a reluctance to use the healthcare system. Each participant had stories of health system use that included feelings of discrimination, racism, and/or marginalization, highlighting the damaging effects of racialization in everyday lives (Reimer-Kirkham & Anderson, 2002). Notable is the fact that a few community members had difficulty recalling positive healthcare experiences, despite explicit attempts to elicit stories about both positive and negative experiences. As discussed in Chapter Six, for many but not all participants, the health system was not readily viewed as a safe and helpful place where they would be treated with respect and compassion.

Overview of Chapter Seven: The Organization and Delivery of Arthritis Services

The final findings chapter addresses the third research question: How does the organization and delivery of arthritis health services affect the ability of these services to be aligned with the needs of First Nations individuals with arthritis? The findings reflect the data collected in the arthritis services field, which included immersion in arthritis services institutions and interviews with healthcare providers who provide arthritis services. These findings discuss the ways in which arthritis services are organized and delivered and the factors that are active in shaping services.

The findings about health services suggest that currently, arthritis services are not well aligned with the experiences of First Nations peoples with arthritis. Despite the fact that almost every healthcare professional interviewed was committed to and compassionate about arthritis patients, they were constrained in their ability to meet the needs of many Aboriginal patients. Culturalist discourses and ideologically driven programs based on self-management discourses shaped the ways healthcare professionals viewed Aboriginal patients, resulting in a significant potential for Aboriginal patients' needs to be unmet. Further, the push for fiscal conservatism has reinforced the biomedical tendency toward reductionism and, in doing so, has left little room for professionals to attend to the social and material context of people's lives, for instance housing issues on reserve and experiences of suffering. Currently, the high tech, highly specialized arthritis services that focus on rheumatoid arthritis have limited ability to address the burden of arthritis, and chronic aches and pains, in First Nations communities; however, there is good potential to enhance the services provided by integrating critical social knowledge into these settings.

CHAPTER FIVE: “WHY DO I HAVE SO MUCH PAIN?”

In this chapter I discuss the experiences of aches and pains as described by community participants. Despite using language (i.e. aches and pains) that offered a potential for participants to view their experiences outside of a biomedical diagnosis, many participants used the term arthritis and most discussed their pain in ways that were limited to physical experiences. However, discussions of pain often served as an entry point to discussions about experiences that reflected social suffering. Participants’ experiences of pain were often intimately tied to social issues such as poverty, and grief and loss. Because of the need for anonymity, in the representations of participants’ stories in this dissertation, some of the details within participants’ stories or demographic descriptions have been changed.

This chapter is organized into four subsections. The first explores the theme for this chapter *For Every Ache There is a Story.* As discussed in the second subsection, for some participants pain began early in life, setting the stage for how participants interpreted and responded to subsequent pain experiences. The third subsection explores how participants made sense of their pain. Often, the stories that participants shared underscored physical causes of pain related to the *Wear and Tear of a Hard Life*. In the final subsection of this chapter, I explore the role of social suffering in shaping participants’ experiences of pain. I discuss the ways that experiences of poverty, interpersonal violence, and grief and loss contributed to and shaped pain experiences. This chapter reveals how participants’ experiences of pain are embedded in the social, economic, and historical context of their lives.

For Every Ache There is a Story

As an interviewing technique, related to a decolonizing orientation, participants were encouraged to discuss stories about their pain, and participants shared a multitude of stories.

Most participants told a specific story for each of their many bodily locations of pain.

Almost all participants reported significant (i.e. moderate or severe) and widespread pain. A common response to the initial interview question "tell me about your aches and pains…" was the question, spoken partially in jest, "shall I start at the top of my body or the foot?" An example was this woman in her late fifties who noted, "I had a body scan…I think that was, when, in the early 90s, and my doctor told me I had arthritis in all my joints. Like, right from my neck, down to my ankles…" (P11). Similarly, a man also in his fifties reported, "wrists, yeah, elbows, shoulder, neck, back, lower back, hip, both left and right now. My left knee, my right knee…. both my ankles, middle of my foot, right where I stepped in that hole…" (P04). While it is relatively common for people living with ongoing pain to report up to four sites of pain (Smith, Elliot, & Hannaford, 2004), the number of sites reported by most participants was between six and ten.

In the stories that participants shared about each painful site, life contexts that included physical, emotional, and psychological hardships were revealed. For example, much was revealed from this brief story shared by a middle-aged man:

> P[28]: Yes. Most of them are probably from playing ball hockey on cement for three hours a night for 12 to 15 years. And some… bottom of my arms, my shoulders and my elbows are from [slightly older relative] beating me up every day for 16 years.
>
> R: Right, right. I remember you saying that. Um… there was also a bike crash, I remember…
>
> P: There was a whole bunch of those…A couple of good bike crashes. Yeah, there was lots of drinking and fighting for me… (P06)

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[28] The designation of P indicates a community participant and the designation of HCP indicates a healthcare professional participant. Following each excerpt, the participant code number appears in parenthesis. The designation of R indicates myself as the primary researcher. The designation of R1, R2, and R3 indicate the three research assistants respectively.

This brief excerpt (details of stories were shared elsewhere in the interview) foregrounds several themes that are discussed in this chapter. One is the historical lack of infrastructure in this reserve community. Safe play spaces are now more readily available, and hockey is played in the gym on a smooth surface. However, infrastructure is still lacking in some areas, as explored below. A second important theme is how intersecting dimensions of social suffering, including interpersonal violence and substance use, shaped pain and arthritis experiences. Hardships experienced by participants were multiple and often overlapping creating a web of factors that played a role in reinforcing, exacerbating, and perpetuating pain. The tone of this excerpt reveals a third theme, that, for the most part, participants did not seem overwhelmed by their circumstances and ongoing pain. Some spoke of intermittent periods of despondency or depression, but most spoke in a matter-of-fact tone about their life and their pain. They seemed to accept *what is*. Indeed, participants' stories, though speaking of hardship, were often infused with humour and laughter.

However, many stories described a difficult life event. For example, most stories about causes of pain described an unfortunate incident that had resulted in a physical injury. These stories are explored in detail in the following subsection *The Wear and Tear of a Hard Life.* In other stories, it was the responses of others that were featured as difficult. These tended to be cases of unexplained pain where the responses of health professionals, and others in positions of authority, were problematic. An example of this kind of difficult experience was a woman in her late 30s, who was raised in foster care[29]; for her, and others who were raised under government guardianship, foster care included experiences such as neglect and abuse. In the excerpt below, she recounted her first experiences of pain as a child of four or five. Although the participant was taken to a physician to diagnose her severe pain, no physical trigger for her pain was found (yet, as a young adult she was found to have a structural deformity of her spine: scoliosis). As a result, she was expected to "just live with" (P19) her pain; she reported that no treatments or remedies were suggested or provided. Instead, she was punished for her pain experiences:

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[29] During the 1960s, 70s, and 80s, large numbers of Aboriginal children were removed from their families and adopted by non-natives. Termed the "sixties scoop," this practice left many Aboriginal children isolated from their relatives and yet isolated in the non-native community because they did not *fit in* (Kirmayer et al., 2003). As

> P: [my pain was] in my legs and my back. They would shoot from my legs to my back. I would wake up screaming, and I lived in foster care – they used to beat me up for it, waking up the whole house [pause 2 sec]. (P19)

This woman recalled that as a child she "never got any sympathy for my pain." Today she keeps her pain experiences to herself. This excerpt offers insight into how the pain experiences can be profoundly shaped through the delegitimizing responses of others (Craig, 2009). For this woman, memories of childhood pain were inextricably linked to memories of neglect, abuse, and dismissal; her current bodily pain, which included but was not limited to her back pain, served as a reminder of this history. This example underscored how current pain experiences were intimately linked to histories of pain experiences.

For many participants, ongoing pain was described as having always been a part of life. For instance, one participant, a middle-aged man, joked that his aches and pains started shortly after birth: "It all started back in about 1958 [chuckles]…" (P12). These kinds of comments normalized pain as being an expected part of living. They suggested that ongoing pain was a persistent reality that began in childhood. Childhood pain experiences set the foundation for pain

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Canadian statistics show (e.g. see Statistics Canada, 2003), First Nations children continue to be placed in foster care. First Nations children are the largest group in foster care; their numbers far outweigh their representation in the general population. One in 10 Aboriginal children is in foster care compared to one in 200 non-Aboriginal children.

experiences that followed; each experience built on the last, reinforcing and reaffirming the *naturalness* of ongoing pain in participants' lives.

A Childhood Filled with (Growing?) Pain

Significant childhood pain was reported by approximately half of the participants. According to participants, childhood pain was typically explained as growing pains by health professionals when a physical cause for the pain could not be identified. Two women vividly reported that they eventually rejected this explanation once they had surpassed the stage of growing and yet continued to experience pain. As this woman, who was eventually diagnosed with scoliosis, explained:

> P: So through all of these years, I had what they considered "growing pains", and when I was 18, I finally got a little annoyed… I hadn't grown since I was 16, so "growing pains" didn't exactly fit the bill any more. (P19)

The woman's use of the language of "annoyed" was juxtaposed to observational notes from the interview that recounted the anger and frustration revealed by her body language and tone of voice. These negative emotions, fueled by healthcare professionals' dismissal of her pain, probably exacerbated her pain as it is well established that negative emotions intensify pain experiences (Clark, 1999; Gagliese & Katz, 2000). Like other participants, and indeed most other pain patients and also most healthcare workers, this woman as a young adult actively sought a physical explanation for her pain, in keeping with the common notion that only pain with a physical cause can be legitimized (Gagliese & Katz). Since, as a young adult, this woman did identify a physical trigger for her pain, as a child she may have experienced a premature/unwarranted attribution of her pain as unexplained; being constructed as Aboriginal may have impacted her *believability* (Browne et al., 2011). Indeed, her memories of not being believed are strong, as evidenced by her wish expressed later in the interview, "to be believed, by them.” The childhood experience of pain dismissal laid the foundation for this woman’s belief that the health system had little to offer her for pain management.

Although rare, a few participants discussed childhood experiences of abuse that were connected to their current ongoing pain. These narratives suggested that experiences of abuse were originally suppressed related to a desire to avoid discussions on the topic. For instance, one woman, who described a childhood characterized by a volatile relationship with her parents, revealed that she originally feared abuse disclosure related to a fear of being apprehended by government officials, a common history for many First Nations peoples (Greenwood & de Leeuw, 2006; Kirmayer et al., 2003); later in life she continued to be reluctant to discuss this aspect of her pain with her doctor:

> P: I was about 11 and I started to… the severity of the pain just started to come, like, out there more. But you know… I didn’t actually start talking to her [the physician] about it until I was, like, 12 or 13. But because I felt like if I told her, you know, what kind of pain I was experiencing or what I was going through, whether they would tie it into physical abuse or, you know, whatever. So I had this fear of telling anybody um, what I was experiencing. Just ‘cause I didn’t know where it would lead…Yeah. I know I have no fear of apprehension now, so I don't know why I shouldn't be able to talk to her [the physician] [laughs] about everything. I mean, I know I don't [now] have to be afraid of being apprehended or taken away from my parents… (P21)

This excerpt shows how the history of child apprehension in First Nations communities interfaced with pain experiences in childhood. In cases where pain was linked with physical abuse experienced as children, participants had been reluctant to share details of these factors with others in positions of authority, including healthcare professionals; this pattern of suppressing disclosure continued throughout adulthood. The silencing of disclosure had consequences for the pain experience; it interfered with seeking and obtaining help for emotional and physical issues.

The data from this study suggested that the suppression of experiences of abuse went beyond avoiding disclosure to health professionals but also to a resistance to connect these experiences to ongoing pain. For instance, later in the narrative, the woman in the above excerpt discussed her personal struggle around actively resisting making the connection between abuse and pain. Not only did she avoid discussing her abuse-related pain with her doctor (and most everyone else) for fear of the links that might be made between her pain and her experiences of abuse (which continued in her adult life), she struggled with acknowledging the link herself:

> P: Um, I get really confused about what is actually [pause 3 sec] am I feeling… is my body or is my bones feeling arthritic today… or are they feeling um, the memory of different beatings. Are they feeling the after-effects of having things um, broken and bruised and that's what confuses me…I can't go there today. Even my dad, you know, I love him, God bless him um, but I can't go there today and the kid's father, I closed that book and I try never to reopen it. I haven't addressed that yet. I haven't gone… I haven't talked to my counselor about it; I rarely talk to her about it. But um, I don't want to be angry. I don't want to be resentful. So when I try to label my pain or my suffering, I want to be able to stick it in that box of arthritis, just because then it belongs to no person. It belongs to no one, it just is. (P21)

For her, and perhaps many other participants, it seemed safer to avoid connecting her current pain with her past experiences of abuse. She did not want to dwell on the abuses; she did not want to implicate her parents (or her ex-husband, who she stated abused her physically and emotionally for many years) in her current pain. She suggested that to do so would bring anger and resentment. Elsewhere in the interview, she noted that she really did not want to talk to anyone about her pain because then questions would be asked, questions that she did not want to answer. And so, she seemed to suppress her own experiences and her own knowledge in order to maintain the sense of balance she had achieved in her life. She wanted to make sense of her pain by placing it in the neutral box of arthritis. However, she also noted that this strategy that she, and so many others from the community, had used had several drawbacks: 1) other community members did not *know* her, 2) her doctor did not have the whole story and thus was limited in providing effective help, and 3) her pain continued to worsen. Hence, a pattern of pain emerged that, for many participants, began in childhood. Injuries, accidents, and abuses were experienced and endured. In many cases the sequelae was ongoing pain. However, only neutral/medical contributing factors were usually discussed or even acknowledged; the physical pain was separated from the emotional pain. Childhood abuses were not readily presented as contributing to current ongoing pain.

In many cases, childhood pain set the stage for further pain experiences. Participants who had their childhood pain dismissed or trivialized, like the participant in the introductory section to this chapter, seemed to have developed a sense that to seek help for pain was futile. Similarly, participants who felt a need to hide, minimize, or misrepresent their pain as children, like the participant in the above excerpt, seemed to continue to do so into the future. In childhood, the template to separate the physical side of pain from the emotional side was laid. In the next chapter, I pick up on these themes as I discuss how participants lived with their pain. Here, I go on to discuss in more detail the accidents and injuries to which ongoing pain was most often attributed.

The Wear and Tear of a Hard Life

In the biomedical view of arthritis, osteoarthritis is most commonly explained as being caused by an old injury to a bone or joint, or wear and tear on the joints over time (Shrier, 2004). Perhaps then, it is not surprising that the stories that participants told about their aches and pains most often included stories of injuries or wear and tear. What was unique, however, was how linked the stories were to background issues of social suffering.

Physical hardships, to which ongoing pain was attributed, came in many shapes and sizes. For instance, one elder woman spoke of her many years, while child-rearing, in a remote location where *a hard life* reflected much physical labour to accomplish the necessities of life. In the view of this elder, years of hauling water and other “back-breaking” work accumulated to result in arthritis of the neck, shoulders, back, hands, and feet.

For other participants, it was their employment, for example years of manual work in a cannery or fishing, which created the physical hardship that underpinned their ongoing pain, particularly aches of the hands. Such was the case for this middle-aged man who attributed his “rheumatism” to years of outdoor work:

> P: So that's where some of the pain and that started too…all the hard work and stuff that we've done and… some of it is just working in the elements too, eh. Most of the stuff I've done is all outside…Yeah, rain or shine and snow…Yeah, I've done anything and everything you could think of outside…work there with uh, recycling- recycling company. Packing endless piles of soaking wet cardboard, paper bags, paper… (P04)

In this example, it was the type of prior employment that was linked to current pains. It is well established that work opportunities for First Nations peoples are shaped by historical ideas of what kinds of work are appropriate for Aboriginal peoples (Lutz, 2008) as well as current social contexts where educational attainment is constrained (Adelson, 2005). Since many participants held physical and manual jobs, the nature of employment was featured as an important precedent for pain/arthritis.

In addition to the wear and tear reported by participants, many participants also shared stories of injuries that were linked with ongoing pain. Injuries from bicycle accidents, car accidents, and falls were heavily represented in the stories told. However, bicycle accidents, often incurred years earlier, were the most common reported source of injury. The high prevalence of bicycle accidents was related to the fact that many community members used bicycles as their primary mode of transportation, being unable to afford a car. This excerpt from a middle-aged man illustrates the long-term impact of a bicycle accident on his physical body:

> P: … yeah, and then that biking- biking injury too I had. I smashed into a car one day, me and my [relative, name] were out having a good time there and got carried away…some

> guy had his car parked out on… a little bit too far out on the road…[in the hospital the nurse says] “We can't do nothing with you sir, you're too drunk." Cripes, so I spent five hours laying up in the hospital there waiting for them to fix up my stitches and stitch me up…I noticed more- more pains and aches after that. (P04)

This man’s story about this bicycle accident underscores a link between the accident and a context of life that was shaped by poverty and alcohol use.

Car accidents and falls were other common sources of injuries to which participants attributed their ongoing pain. Similar to bicycle accidents, these sources of injuries were shaped by intersecting aspects of participants’ lives. For some participants, intoxication played a role in the accidents that led to injury and ongoing pain. Such was the case of one man in his mid-fifties who recounted a past that included addiction to alcohol. He noted how intoxication was linked with the car accidents and falls to which he attributed his current day arthritis. In this excerpt, he recounted a fall that seemed to entrench his arthritis in his body:

> P: And then, like about, like about four years ago when I, when I last drank, I, I rode down some… two flights of concrete steps…Yeah, and uh, th- that’s when I really, that’s when I really got damaged, my whole body like the insides and concussion and everything…and that’s when the arthritis got really bad after that… (P13)

According to this participant, the role that alcohol use played in giving rise to and exacerbating his arthritis, finally led him to address his addiction to alcohol.

For those participants who struggled with addictions and substance use, intoxication intersected with experiences of aches and pains in a number of ways. While intoxication was sometimes used to diminish the pain, it was also characterized as contributing to pain. One participant, a middle-aged man, was able to articulate this complex relationship:

> P: And… as I said, the emotional hurts when I was younger probably led to the drugs and alcohol. So that deteriorated my health, so that every injury I got was probably worse because of the health…. Like I would have been a lot healthier if I wasn’t an alcoholic from the time I was 16 on. I would have been a lot stronger, when I was 24… then that injury wouldn’t have been as bad [pause 4 secs]… (P06)

On the one hand, addiction to alcohol and other substances seemed to be related to a desire to mask or endure pain and suffering, perhaps including the pain and suffering that has resulted from historical trauma[30]/the colonial history (Brave Heart, 2003; Furniss, 1999). On the other hand, addictions and intoxication were sometimes discussed as contributing to pain, either as a factor in a bicycle or car accident, or as a contributor to the overall weakening of the body, making it vulnerable to problematic healing and hence ongoing pain. Because substance use and addictions in First Nations peoples have been linked with a colonial history (e.g. Brave Heart; Duran & Duran, 1995; Furniss), for the participants of this study, a history of colonialism was linked with experiences of aches and pains.

Substance use and addictions were not the only colonial links to experiences of aches and pains. Poverty, poor community infrastructure, and/or community politics also figured prominently in stories of accidents and injuries that were situated as precursors to pain. A particularly poignant example of the intersecting influences of these structural issues on injuries and ongoing pain was the situation of one elder woman who lived on the reserve in a shack that had been condemned multiple times by authorities because of its inadequate walls and windows, wiring, and plumbing. Observational notes from a home visit and comments relayed by research assistants indicated that her home was a trap for falls. In her narrative, she explained that she had already sustained one injury, where she injured her knee, because of a lack of safety equipment in the bathroom. Although the bathroom had been fitted with grab bars, the bars had come off the walls because there was nothing solid in the walls to affix the bars. Her knee injury, three years old at the time of the interview, was a significant source of ongoing pain and disability, and had led to an unsteady gait. As such, she was at a high risk for another fall. As she discussed in the quote below, the stairs going down to her basement, where her laundry facilities were, posed a particular danger for her since there was no handrail:

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[30] Maria Yellow Horse Brave Heart (2003) describes historical trauma as the “cumulative emotional and psychological wounding, over the lifespan and across generations, emanating from massive group trauma experiences” (p. 7), such as those experiences of oppression, racism, and discrimination propagated against North American indigenous peoples through colonial laws and practices.

> P: Really difficult. I've asked [name] now for a rail, at least on the outside. 'Cause…they're real narrow and really steep…So I just sort of lean on the wall on the other side when I'm going down…And I, at least twice, I've asked [name]. He said he'd get somebody in there, do it right away.
>
> R: When was that?
>
> P: Five years ago.
>
> R: Everybody has a different definition of “right away”.
>
> P: I know. [laughs] This is [name]. Yeah… (P16)

The elder here did not seem overly concerned about the community’s lack of action on her behalf. Although she spoke frankly about her difficulties, her comments suggested that she was not really expecting the community to act. Earlier in the interview, she explained that she understood the community’s reluctance to put money into her condemned house, despite the fact that this seemed to be the only viable option since she did not have the financial resources to afford to rebuild. She was a senior living on a fixed income and helping to support others in her family:

> P: And I hate to see the money just go to waste too and… like, for instance, our plumbing, we've had to get [name] in now, twice, with a leaking faucet…the floor was always wet in front of the sink and he's come in twice. And this last time, he's… “there is no way I can just replace the tap anymore. I have to change the whole system”, and they [community decision-makers] don't want to put the money into new plumbing. (P16)

This elder, like other participants, endured living conditions that put her at great risk for injury and subsequent ongoing pain. The reality of inadequate housing (1/3 of houses on Canadian reserves are in need of major repairs; FNC, 2005) puts many community members at risk for falls. These falls were often implicated as precursors to, or aggravators of, arthritis.

Although this elder seemed poised to continue to live in the home, her acquiescence was not without consequences for her and her two grandchildren who lived with her in the home:

> R: The question I'm wondering about is, how do you feel about living in that house? …
>
> P: It's stressful, causes all three of us so much stress. (P16)

The role of stress and distress in participants' pain experiences are discussed in the following subsection.

This elder's predicament underscored the potent implications of intersecting structural inequities (e.g. her own poverty, the community's poverty, and imposed housing regulations through Indian and Northern Affairs that constrain her ability to profit from land) on pain and disability, as well as the complex ways that suffering was perpetuated. She had repeatedly asked the community for help to make her living arrangements safer, and while they had assisted in the past, they currently seemed to have given up trying to sustain the house. This particular elder was quiet and unlikely to demand assistance. Her comments suggested that she had accepted the community's view that it was not "worth it" to try and improve the house. She continued to live at risk because she saw no options otherwise. Likewise, the community seemed to be out of options to help her. There were no funds to build a new home and she had refused (owing to distrust and fear of loss) a recent plan that would have additional housing built on her land as a way to fund new housing for her. Herein lay the complexities of intersecting structural inequities that contribute to social suffering and ongoing pain.

Aches and Pains and the Context of Social Suffering

In this final subsection, I explore how three forms of social suffering commonly represented in the stories of participants, poverty, interpersonal violence, and grief and loss, shaped the pain experiences of participants through their material, physical, and emotional consequences. In some cases, these experiences contributed to the pain experience by enabling injury. In other cases, these experiences contributed to participants' pain in more subtle ways, often not acknowledged by participants.

Financial Stress

The stories told by many participants reflected financial resources that were barely adequate to meet basic needs. Poverty has multiple points of influence on the pain experience. For example, poverty can contribute to the pain experience through the adequacy of housing (as discussed earlier), the availability of nourishing food to heal injuries, and through access to goods and services that can be purchased to assist with or ease suffering (I take up this point below). In addition to these physical/material effects, poverty is a source of distress as people worry about their ability to secure adequate financial resources and contemplate difficult decisions as to how best to use these limited resources. Participants' comments about their financial means often suggested a kind of existential distress/pain, as financial insecurity made a mark on their sense of identity (Fiske, 2006): "usually, financial things stress me out the most" (P08). However, although many participants commented on the distress associated with living in poverty, they did not typically connect this distress with their pain experience, despite the plethora of literature that documents the synergy between distress and pain (e.g. Craig 2009).

In this section, as an exemplar, I focus on one material consequence of inadequate finances that had implications for participants' pain. For those participants who lived with marginal incomes, an important factor that seemed to exacerbate pain experiences was the lack of appropriate sleep surfaces. Approximately half of the sample spoke about *mattress issues* and the corresponding sleep disturbances. Most described sleeping on old and/or second-hand mattresses that failed to provide a comfortable, restful sleep. An example was this middle-aged woman who struggled with finances, who said, “I have a hard time getting to sleep… got a bed, it was a free bed, it was from somebody from the Band Office….She just wanted to give it away… so I thought, well, I’ll try it” (P02). The interconnectedness between sleep and chronic pain has been well-noted in the literature (e.g. Miaskowski, 2009) and participants described how a lack of sleep fed into a cycle of escalating pain.

In another instance, one participant, an elder woman, used her residential school government cheque to purchase new mattresses for everybody in the household (herself, grown children, and grandchildren). This was the first time that anyone (with the exception of one grown child) had ever had a new mattress to sleep on. The elder recounted the day the new beds arrived, “That was quite an emotional moment there, getting all those beds, everybody teary-eyed…” (P03). One grown son, interviewed for this study, reported significant improvements in sleep and thus pain, following his receipt of a new mattress:

> P: …before we got these new beds there …it might take about almost an hour there to roll out of bed. So I'd be waking up, like, 6:00 in the morning and then finally get out of bed about 7:00… stretching and trying to get- to get out of bed [laughs]… (P04)

For many in this sample, the lack of adequate finances contributed to the lack of basic necessities, such as adequate sleep surfaces, which had implications for the pain experience. Social suffering has material consequences, which compounds suffering, in particular the experience of pain.

“Nothing to Brag About, Being Abused”

In some of the stories told by participants, the context of violence came sharply into view; six participants talked directly about enduring physical violence and a few others indicated that “violent outbursts,” but not necessarily physical harm, were part of their existence. Given that many communities often create a form of censorship against disclosure of abuse (LaRocque, 1994), this amount of discussion was significant. That participants in this study felt comfortable to discuss prior abuse probably relates to the fact that all discussions occurred in the context of an interview where the research assistants were trusted people, suggesting that when a safe, discursive space was open, participants were comfortable in discussions.

As noted earlier, participants who discussed prior abuse typically noted that they had delayed disclosing the abuse for many years. For instance, one participant, a single mother of three in her thirties, noted that she had resisted disclosure of the abuse she suffered for a number of years, even to her family. She linked her lack of disclosure to shame, “even my eye [which was injured during an episode of interpersonal violence] felt ashamed” (P20). In this participant’s narrative, she described an abuse cycle that included abuse, injury, self-blame for the abusive behaviour, shame, avoidance of disclosure, and hence more abuse. These feelings created, for her, a huge barrier to seeking help for abuse-related painful conditions. As LaRocque (1994) explains, a lack of disclosure perpetuates the cycle of abuse and hence pain.

In most instances, violence was construed by participants as contributing to pain and suffering because it led to injuries that later became a source of ongoing pain. One woman in her thirties reported childhood violence perpetrated by both her parents. In her narrative, she discussed abuse that was sustained over a number of years. In this quote she noted how the onset of her ongoing pain, diagnosed as arthritis by her physician, coincided with the most tumultuous year of her parents’ relationship:

> P: Yeah, when um, I actually started to, to experience pain when I was, like, 11 and um, 11 was pretty much the last year of my parent’s relationship and the last year was just horrible. They um… so a lot of their frustrations ended up coming out and being heaped on the wrong people in physical ways. (P21)

This participant, although tentative, described a link between past abuse suffered and injuries sustained, and current, ongoing pain.

The difficult issue of violence against women has been recognized as an important and prevalent problem in many Aboriginal communities (LaRocque, 1994), and has been directly linked to the effects of colonization (Brownridge, 2008). In this study, the violence experienced by some woman participants caused injuries that were described as sites of ongoing pain. An example of this was the case of one woman in her forties who provided a factual and monotone account of an episode of violence that left her with injuries she attributed to her ongoing pain:

> P: And then, I guess [pause 5 sec]... probably, like, 15 years ago, I was beaten really bad. I have a fracture here… And then I was hit on the left side of the head with a fist… So, there's TMJ, and then something wrong with my ear from being hit so hard. And then I bounced off of the bar and hit the weight, so there's, like, fractures and dents here…But I did mention it to the doctor that I'd had my head beaten in before, and she just kind of... never examined it. And I told her about the TMJ, that it's there. You can see the bruise right there, but it was never really diagnosed, just that I know what it is. And she [the doctor] doesn't... there's not much you can do for it. Medication might help…and what else happened... During when he was beating me up, he decided he wanted to bounce on my right hip and kick me…and jump up and down on it. That's where I have the worst nerve problems, is my hip. (P05)

Women who have experienced abuse-related injuries are more likely to have ongoing pain and disability owing to the complex interaction between the stress response and the lack of complete healing from the trauma (Wuest et al., 2008). For this participant, a lack of complete healing may have been related, in part, to a dismissal of her experiences by her healthcare provider.

For some participants who experienced intimate partner violence[31] (IPV), and who had ongoing pain related to injuries sustained during abusive episodes, current experiences of pain brought up traumatic memories of abuse. In the following excerpt, a participant talked about the sequelae from an episode of IPV that she experienced:

> P: So ever since then, um, I guess when they [my family] see me emotional, they [pause 3 sec] ask if it's my face that is hurting. Because it took me a long time to tell them that he

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[31] IPV is a pattern of physical, sexual, and/or emotional violence by an intimate partner in the context of coercive control (Wuest et al., 2008).

> did a pretty good number on my face…he frickin' punched both my cheekbones, and this one really hurts….
>
> R: So that one really doesn't go away?
>
> P: No…it just reminds me of the abusive times that I had with him because it throbs so much.
>
> R: And then that memory is right there.
>
> P: Yeah, [pause 4 sec] yeah. (P20)

For this woman, her ongoing pain was a constant reminder of the abuse she suffered. As she described, she relived the abuse each time she felt the pain. The physical experience and the emotional experience cannot be detangled from each other nor the past, as the past "is a living and resonant part of the present" (Marker, 1999, p. 17).

The traumatic experience of violence can contribute to the pain experience in a number of ways (Wuest et al., 2008). As described above, a physical injury can contribute to pain. Moreover, the physical response of the body to stressful memories or encounters can be muscle tightening and tension, which can exacerbate pain. Several participants described stories that referred to violent episodes. Regardless of whether or not an injury was sustained, contexts that included violence fostered a backdrop of physical tension and distress in participants: "I feel sicker, or I feel sadder, or I feel more emotional. And, uh, I…feel it in my neck and my spine" (P18). This backdrop fed into the pain experience. During my immersion in the community, nearly every woman I talked with, over the age of 30, had at least one (and usually many more than one) story of abuse. Hence, experiences of violence and abuse may be a more common contributor to ongoing pain, particularly for women, in this community than in some other populations.

“I Got Pain in Me”: Grief and Loss

Many participants in this study spoke about how they were profoundly affected by multiple losses, including the deaths of loved ones. In addition, during data collection, the suicide of a community member deeply affected several members of the research team (CRAs and members of the CAC), as well as several participants. I observed firsthand the many ways that this tragic event contributed to the long-standing pain that so many community members endured. The intent of this subsection is to show first how emotional distress is perpetuated and exacerbated, and then how emotional distress and physical pain are mutually reinforcing (i.e. pain compounds emotional distress and emotional distress compounds pain).

Participants’ stories revealed how emotional distress is perpetuated and exacerbated to create a persistent backdrop against which pain is experienced. Experiences of a death in the family or community were a common cause of emotional distress for participants. Unfortunately, since suicide rates in some First Nations communities are high, related to a complex array of historical and current factors (Lalonde, 2006), for many participants, grief and loss associated with deaths from suicide and/or other causes interconnected with each other to form the conditions of their lives (Brave Heart, 2003; Haskell & Randall, 2009).

For one elder participant, unresolved grief from the loss of her child exacerbated her distress when her nephew died due to suicide. In her narrative, she explained: “I got pain in me. It's all come back again, it's hurting…I can't take it” (P09). The words of this elder underscore how emotional turmoil can lead into a cycle of escalating distress. For many participants, the death of a loved one initiated a complex emotional response that connected the current loss with the multitude of other losses they had experienced in their lives (Brave Heart, 2003; Kirmayer et al., 2003). Because of the tight-knit nature of this community, a death of any member had a significant impact on almost every participant. During the course of my immersion, there was approximately one death within the community every four to six months reflecting the high mortality rates for First Nations peoples (in some cases First Nations experience double the rate of premature deaths than other Canadians; Martens, Sanderson, & Jebamani, 2005b). Unresolved grief, including grief from historical trauma, is a common stressor for many indigenous peoples (Brave Heart). The past remained present in the everyday lives of community members, compounding grief, loss, and emotional distress and creating a context, as I show below, that was ripe for escalating the experiences of pain.

For some participants, the experience of pain itself was interpreted as a loss, particularly when the pain experience included a restriction on mobility. For some participants, aching joints meant that they were limited in their ability to perform culturally significant activities, such as cedar work or weaving. Others discussed their limitations in being mobile in the community or in performing activities of daily living, some of which had been a source of happiness such as gardening or walking in the bush. Participants’ reactions to such pain-associated losses were sometimes anger and frustration (especially when they struggled to get satisfying medical help) and other times depression. The following middle-aged man noted that his pain contributed to feelings of depression:

> R: There's a question here about emotions and does having… being in pain, trigger emotions for you?
>
> P: Some days yeah. See? That's about it.
>
> R: Can you describe the emotion?
>
> P: Depression. (P04)

Observational notes from this interview documented a clear shift in the participant’s demeanour as he mentioned depression. During the interview he had been animated in conversation;

however, in response to my question, the participant spoke very quietly, sank lower in his chair, looked to the floor, and rounded his back. It was as though he was experiencing the emotion in the moment, suggesting that the depression was very much there. The CRA had rarely seen any evidence of depression in this man before. This excerpt demonstrates the strong link between pain, grief and loss, and depression.

Grief and loss influenced participants' pain experience in a number of ways. The aspect most commonly alluded to by participants was through a physical mechanism by which physical bodily tension or increased physical contact with others, associated with the grieving process, directly exacerbated pain. This was the case of one elder who, in her narrative, described an exacerbation of the arthritis in her hands during a mourning process. As the family matriarch, this elder had responsibilities in the mourning process that included much contact with other mourners:

> P: Well, just going back to emotional and all that sort of stuff. After [relative] died, I found both this side and this side, that my arms and my fingers, and I couldn't let anybody touch me, because my hands were so sore from people coming and grabbing me. And I finally told them not to touch me…I noticed after that that my hands really ached…for a couple of weeks after that, where it was really hard to do anything. (P03)

For this participant, the physical activities that accompanied the grief process were identified as contributing to pain. Her grief and loss experience contributed to a "flare-up" of her bodily pain. Her response to the pain was to isolate herself from others. Her narrative revealed that this response itself was a source of distress for her, since she felt incapable of assuming her matriarchal responsibilities. Here was the cycle of distress-pain-distress and then ongoing pain, which for her lasted several weeks.

The previous excerpt suggests a second mechanism by which persistent grief and distress influenced experiences of pain, through the biochemistry of chronic distress, which can make the body vulnerable to pain (Wuest et al., 2008). For example, chronic stress may eventually result in low cortisol levels (related to adrenal fatigue), leaving the body more sensitive to pain. As well, chronic stress can increase proinflammatory cytokines that may increase the body's autoimmune and inflammatory response, which can exacerbate arthritic conditions (Wuest et al.). There are many ways that neurochemical activity associated with distress feeds into the pain cycle. While the elder above suggested that physical stimuli was the cause of her exacerbated arthritis, the fact that the pain persisted after the physical stimuli was gone, but yet the grief remained, suggested that the grief alone was a factor in the pain experience.

For many participants, emotional pain fused with physical pain. This was illustrated by the words of one elder man:

> P: Yeah. I'm just wondering, like if uh arthritis, like uh, like has something to do with like depression. You think, you think uh? …Like I was talking to a couple of people just the other day about physical pain and just pain you get like what do you call it? Mental pain or whatever? Yeah. [pause 3 sec] It's pain, you it's… I get uh two or three different kind of pains eh [laughs]. (P13)

While many participants, following a biomedical interpretation of physical pain, tried to separate their many experiences of physical pain from their many experiences of emotional pain, their narratives reveal how inextricably linked pain experiences were to losses and other forms of distress they experienced as part of their daily lives. One participant commented directly on the inseparability of this many pains:

> P: Plus and then the age bracket too eh. Forty six…[doctor said]"You shouldn't have it [chronic pain] this bad, this long." I says, "You've never lived in my shoes have you?" He goes, "Oh, yeah, it's true." 'Cause after he said he… he sat down and he looked at it eh and he looked at my chart. Then he noticed eh all the aches and pains of over the years of finally combined all together there to be just one big pain. (P04)

As this participant noted in his narrative, the toll on his body, in the form of ongoing pain, was unexpectedly high, owing probably to the stream of hardships and losses he had experienced. He noted how all the different experiences in his life were each integrated into a whole pain experience. Participants experienced pain as an integrated experience that was heavily shaped by the psychological, emotional, and social context of their pain experience. For many of the participants in this study, their psychological and emotional milieu included repeated experiences of loss resulting in ongoing grief and depression. While these negative experiences were not usually foregrounded, they often simmered below the surface. Whether suppressed or not, experiences of grief and loss were entwined with pain experiences to become an integrated experience of pain/suffering.

Summary

The findings from this study make visible the powerful link between the pain experiences of participants and the social, historical, and political context of their lives. The context of participants' lives, shaped by more than a century of colonial politics, fostered hardships that took their toll on participants' bodies over time. In most cases, the context of participants' lives (e.g. manual work, poor community infrastructure/housing, poverty, interpersonal violence) created circumstances that led to injuries, either through wear and tear or accidents. However, the backdrop of emotional distress experienced by many participants also contributed to the pain experience, often in unacknowledged ways. The multiple and ongoing losses experienced by many participants were entwined with physical pain, as distress exacerbated pain and pain led to distress.

For many participants, experiences of hardship began in childhood and continued throughout their lives. The sheer number of these hardships experienced helps explain the extent of pain reported by participants. Despite the ongoing hardships experienced by so many participants, a feeling of strength and resilience reverberated through almost all the interviews.

As I explore in the next chapter, most participants were active in their lives, used humour in their descriptions, and were determined to continue on regardless of the many challenges they faced.

CHAPTER SIX: “I’VE JUST LEARNED HOW TO DEAL WITH IT.”

This chapter discusses the data that inform an understanding of how participants *lived well* with their aches and pains. Consistent with a decolonizing orientation and Aboriginal epistemology, in this chapter I characterize the actions and responses of participants towards their aches and pains as *living well with aches and pains.* I begin with a discussion of participants’ stories about living well that point to a community norm, which I have labeled *suffer in silence.* This norm brings together discourses around suffering and silence that played an important role in shaping participants’ responses and actions. The second section of this chapter discusses the resources that participants used for living well. Although I discuss the role of family and traditional medicines, given the focus of this dissertation, the bulk of this section examines participants’ use of the health system. Most, but not all, participants were reluctant users of health services. Nonetheless, every participant had considerable exposure to the system over time. In this chapter, I show that while participants had some challenges in their efforts to live well with their aches and pains, overall they described considerable strength and determination.

The phrase *determined acquiescence* seemed to capture the approach to living well with aches and pains that was characterized by most participants. The first term *determined* reflected the refusal, that most participants described, to let the pain prevent them from living their lives as they saw fit. Participants typically noted that they had dealt with many hardships in their lives; they were not novices in the world of pain and suffering. Indeed, the comments of many participants suggested a normalization of pain and suffering. Herein lies the foundation for the second term *acquiescence*. Many participants seemed to accept their pain without complaint. This was especially reflected in participants’ comments about their relations with the health system; while most described going through the motions of accessing health services to some degree, many said they did not expect too much and hence they demanded little and often got less. Determined acquiescence was an orientation that seemed to work for and against participants: it enabled participants to continue living their lives but potentially prohibited them from finding relief from ongoing pain.

Suffering in Silence

Participants' attitudes and responses towards their ongoing pain was shaped by a community-wide norm that reflected the theme *suffer in silence.* This norm was often highlighted in, and thus confirmed by, the many discussions I had with the CAC, elders and the CRAs. The community norm suffer in silence, which suggested that community members ought to keep their pain and suffering hidden from view, tended to encourage participants to stay strong in the face of suffering. It also constrained participants from sharing certain aspects of their experiences of pain and suffering with others, including health professionals. In particular, while participants readily described many instances of hardship/suffering, they rarely discussed the personal impact of those instances.

"If You Don't Have Pain, I Guess You're Just Not Living"

As discussed earlier, the narratives of most participants reflected a lifetime of repeated hardships. The theme w*e suffer* was reflected in the stories told by most participants. The words of one middle-aged man revealed how pain and suffering had become woven into the fabric of life: "That's kind of like how pain is, 'All in a day' [laughs]. Yeah, I could gripe and grumble about the pain, but you know everybody in and around me has got the same, they're all in the same boat…" (P10). This participant noted the ubiquitous nature of pain in his community and the way it had become an integral part of the day. These kinds of ideas are echoed by Dr. Rod

McCormick (personal communication, November 2008), an Aboriginal scholar, who notes that as suffering has become such a consistent part of the lives of Aboriginal peoples, claiming suffering has sometimes become a necessary part of claiming Aboriginal identity (e.g. one is not truly Aboriginal if one has not suffered), perhaps in an attempt to create meaning out of suffering and "valorise it as part of a larger collective struggle" (Kirmayer et al., 2003, p.S20). As participants discussed instances of hardship and suffering, they typically framed their experiences as being an expected part of daily living.

Many of the stories told by participants reflected a particular perspective on suffering. That is, the ability to quietly persist through experiences of hardship and suffering was often a source of pride and inner strength. For instance, one elder (P01) told a story about a time when she was a girl in residential school assigned to clean the chapel. While cleaning, she and another girl consumed some sacred wine and bread because they were poorly fed and hungry. They were caught and whipped; however, the elder proudly noted that she did not shed a tear with the beating, "I didn't want to give them any satisfaction." Her response can be interpreted as an act of resistance against those who had treated her unfairly. Other participants shared similar tales of patience and endurance during adversity. For instance, this elder shared how her experiences of adversity led to inner strength:

> P: There may be times I'm really hard on myself, that I have to, you know, you can't give up. I guess it was that determination of being put down all the time when I was young. You can't give up. (P03)

These stories revealed a strong orientation to show strength no matter what hardship was encountered, consistent with claims made by many First Nations scholars that "we are still here" as distinct peoples despite Canadian policy to eradicate *aboriginality* with forced assimilation (e.g. http://www.nativecircle.com/issues.html). The need to endure, and even be victorious over, whatever experience participants were presented with was embedded in the *we suffer* discourse. This reflected participants' ability to derive an "enhanced sense of worth and empowerment in the struggle to overcome adversity" (Burack, Blidner, Flores, & Finch, 2007, p. S21) and fostered the determined responses to aches and pains reflected in participants' stories.

Many participants talked about their determination to "carry on" and "not let the pain get you down." These responses reflected resilience, which is defined by Dion Stout and Kipling (2003) as "the capacity to spring back from adversity and have a good life outcome despite emotional, mental or physical distress" (p. iii). A particular strategy towards resilience that was represented in many of the stories told by participants was laughter. Nearly every participant exhibited laughter during their interview. Even in cases where, within the stories told, the context of violence, abuse, and suffering was pronounced, stories often featured a victory and were told with a humourous angle that seemed to contradict the context. When I asked the CRAs to help me interpret this experience, I was told "you can either laugh or you can cry and we choose to laugh."

Humour is characterized by Dion Stout and Kipling (2003) as a pro-social (as opposed to anti-social or self-destructive) strategy because it mobilizes protective factors in the process of resilience. The following story, told during an interview with a woman elder, revealed how laughter could be used to deal with negative encounters in the healthcare setting. It also showed how story-telling taught the appropriate way to live well despite adversity:

> P: …my late mother-in-law used to have some real horror stories about when she used to be in the hospital. She used to go in for pneumonia almost every three months. And she was, what 77. And she's in [major urban hospital], half dying. Sicker than a dog. And the doctor, the doctor comes in, and you're never going to believe what I'm going to say. [laughs] It's hilarious. Comes in to her and says, "Mrs. [name], these are young interns, and they want to examine you." And she was so sick, she couldn't care less. So, what they did was, they lifted up the sheets, spread her legs out, and start digging around in her.

> R: Oh, nice. Cervical exam for her pneumonia. [laughter] I don’t know why you’re laughing.
>
> P: The way that she was talking when she came in, and she says, “I don’t know what the heck they were looking for.” She asked the doctor after why they were doing that examination, and the doctor said, “Oh, we thought you were the one that was pregnant.” [laughter]…That was so hilarious. It was so funny the way she was talking about it. She was so angry, and she was just killing herself laughing about being spread out and the young doctors are digging around, didn’t know what they were digging for. (P03)

In this example, the participant noted that her mother-in-law was “so angry” and yet she was laughing. Hence, laughter can be a way of dealing with the anger of unjust experiences.

In the book *Me Funny* (Haden Taylor, 2005), various Aboriginal authors critically examine humour in Canadian Aboriginal contexts. Several purposes of humour are discussed. For instance, Fagan (2005) states that humour is used as a means to “subvert white society and to counter colonization and stereotypes” (p. 24). She also states that humour is used “as an indirect means of thinking through contentious community issues” (p. 43). As such, humour helps Aboriginal peoples resist the effects of colonization, as well as prompt critical thinking about current affairs; it is the “WD-40 of healing” (Haden Taylor, p. 70). Hence, laughter is a tool for both resilience and resistance. Participants’ stories revealed that humour was an essential component to living well with aches and pains; participants seemed to *suffer well* through humour.

“Nobody Wants to Hear Me Suffer”

While community members spoke about instances of suffering most were reluctant to speak about the personal impact of their pain and suffering. Silence, especially regarding the negative personal effects of suffering, was suggested by nearly every participant to be the appropriate response. This orientation was demonstrated in the words of one of the CRAs during her interview as a participant. We had worked closely for over a year and she had been outspoken about pain and suffering in her community. However, within the first minutes of the interview she disclosed how nervous she was about sharing her own circumstances. I was completely surprised. As I reflected on this interview, I realized that while she freely talked about the pain and suffering of others, she had rarely discussed her own pain:

R: So let's talk about your story and your pain.

P: Just so you know, from…right from the get go, I don't really ever do that.

R: Do what?

P: Talk about what I go through. I'm getting better at it though [laughs]. (P withheld[32])

In her narrative, this participant shared the many ways her mode of silence about pain and suffering was learned and reinforced. Her narrative referred to experiences where the breaking of silence carried a potential for harm, through threats of child apprehension and intra-community gossip. These experiences were echoed by other participants.

For some participants, experiences in childhood reinforced silence as the best approach for dealing with inner pain. For instance, the following participant, a man in his fifties, noted that public school experiences had taught him that silence was the preferred way to deal with his suffering associated with unwelcome and derogatory comments made by others:

> P: I think a lot of… speaking for our age group anyhow…we don't speak out and truly express how we feel, because of our experiences even as simply as just being in school. A lot of time, it's just easier to deal with whatever's going on, than to try and express it and say this is what is actually going, because of all the times that we've been knocked down over different things. Like even, so much as a, you know you're nothing but a dirty, drunken Indian. Those stereotypes stay with you your whole entire life, right? (P12)

As a means to limit his exposure to hurtful experiences, this man, like other participants, had learned that it is often safer to keep silent.

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[32] In this instance, and a few others, the participant number has been withheld to protect the identity of the participant who, if linked with other excerpts in this dissertation, might be identifiable.

The lesson to keep silent as a mode of self-protection reflected a backdrop of mistrust that was revealed in the comments of many participants. Almost every participant noted how difficult it was for them to trust others. In describing the magnitude of the mistrust issue in the community, one middle-aged man told this story:

> P: I was in a workshop when I heard a lady from Six Nations in Ontario say… she was walking around the room, and said, “What do you think the Native’s biggest loss was?” Everybody said, “Culture, land, religion.” She said those are all good answers, but I think the biggest loss we suffered as a people was trust. And if we get that back we can get everything else back. So I thought that sounded pretty good. So trust was our biggest loss, like we don’t trust anybody. Even our people… each other…If you can trust yourself and each other, you can rebuild all those other things – religion, culture, and language. (P06)

The above excerpt points to colonial processes as contributing heavily to distrust, and hence silence, in communities. As noted by other participants, residential schooling was important in setting a foundation of mistrust, particularly mistrust in institutions and their authority figures (Kelm, 1999). According some participants, distrust had been transferred to healthcare systems and health professionals as representatives of institutions and authority.

While I was expecting to hear about mistrust issues with community *outsiders*, I was surprised to hear expressions of mistrust within the community. Many participants shared stories that revealed their difficulties trusting other community members. One woman participant suggested that the context of interpersonal violence had fostered mistrust; as discussed in the previous chapter, this context has shaped discourses on silence. For participants, the context of distrust/silence in the community meant that sometimes close friends and relatives were not privy to the extent of the pain and suffering experienced. This context sometimes constrained opportunities for support and assistance that might otherwise have been available.

While the narratives of some participants suggested that silence was learned as a means to protect oneself from harm, in other instances participants reported they had learned to be silent because speaking out about pain and suffering was futile. An example of this aspect of the silence norm was provided by an elder participant who had lived in a remote location for many years:

> P: I guess it's because I've always been alone. When I lived in [remote community], [husband] was working, the kids were in school. I was left alone at the house, nobody to talk to and being in a residential school and being with no money and asking for help, I always got turned down. So I got to the point where, okay, I can't get help, so I have to do it on my own. I got that stuck in my head that, you know, I got to do everything on my own. Nobody's going to help me and nobody's going to be around there. Nobody wants to listen to what's going on with me and, you know, stuff like that. (P09)

As this elder noted, her experiences led her to believe that there was no purpose in asking for help; pain and suffering had to be dealt with personally.

For many participants, lifetime experiences had taught them that silence was an appropriate and safe approach to dealing with adversity. The lesson to be silent, particularly in reference to pain, was actively taught in the community. In the following excerpt, a man in his late thirties recalled how older males instilled and reinforced this lesson:

> P: Like you don’t go whining to anybody every time you get hurt. You deal with it. You take it. You take it, shut your mouth and move on. Do what you got to do…[laughs] …Yeah, you don’t whine around… don’t go crying to anybody. You don’t run home and tell your mom when you get hurt…
>
> R: Yeah. Do you think there’s a link? Like, where does that come from?
>
> P: From the generation above us. You know, they were pretty rough with us. (P06)

Lessons taught within the community intersected with prior experiences to reinforce the community norm to suffer in silence. Although reinforcing discourses were active, they were being resisted by some community members who were vocal about their pain and suffering, and pressing for solutions.

However, for the majority of participants, narratives revealed an expectation that personal experiences of pain and suffering, though ubiquitous, were to be endured privately and not shared with others. Participants showed some comfort in speaking about experiences of suffering that were long past (i.e. childhood) but were considerably less comfortable in speaking about current sources of suffering, particularly the personal impact of suffering. Although the theme s*uffer in silence* dampened participants' efforts to access help for their aches and pains, participants drew on a variety of resources to help them live well despite their pain and suffering.

Resources for Living Well with Aches and Pains

The Role of Family

The family served an important role as a resource for health and healing. While participants seldom discussed actively seeking help from family members, the family assisted them in many direct and indirect ways. Sometimes, participants noted that family members provided direct support in helping to accomplish tasks that were difficult because of pain. Other times, participants noted that family members provided emotional support. For example, one participant, whose doctor had told her she did not have arthritis in her hands, doubted her own experiences of painful fingers; her painful condition, however, was validated by her brother:

> P: Hum, I thought, "Oh, I must be just over-exaggerating about my fingers." But, now when we had that bail of snow just awhile back, my brother was even like, "Holy cow, sister look at you, your fingers are just huge…Are you okay?" (P20)

In this way, family members sometimes helped counter the perceived dismissal of pain that some participants experienced during healthcare encounters.

The narratives of participants also described instances where participants, primarily those who had been diagnosed with arthritis, drew on the experiences of other family members who also had arthritis. In these instances, participants compared their own experiences with their family members' experiences. These comparisons influenced the participant's actions. While in some cases comparisons were helpful because they facilitated an understanding of arthritis and the development of strategies for health and healing, in some instances this kind of comparison was less useful. For instance, one participant told of a time when a health professional had recommended that he use a wheelchair to help him be mobile over long distances, a task that had become difficult because of significant pain:

> P: I didn't want it 'cause I didn't want to be on a wheelchair [laughs] 'cause my sister's on one and she's, I don't know, she could move and walk and everything when she wants to but she's got used to it 'cause it's on one of those electric ones eh. So, I didn't want to go on there. Just the same as I don't want to go to a hospital right there [pause 3 sec]. (P13)

Based on the narrative, the type of arthritis this participant had (OA) was probably not the same as his sister's arthritis (RA). So, it is unlikely that he will "end up" like his sister. In cases where the arthritis of the participant had not evolved in the same way as their relative, comparisons sometimes caused confusion and anxiety. The words of this woman, in her mid-fifties, conveyed her confusion "Um, my mom's is just in one hand, but, for some reason, I'm getting it in both hands" (P11). Hence, comparisons with family sometimes facilitated and sometimes constrained participants' ability to live well with their pain.

Beyond comparisons, participants shared stories about how their own role in the family influenced their strategies for living well with aches and pains. For many participants, the need to fulfill a family role was the most important aspect of their life. All strategies for health and healing were weighed in light of this role. In cases where the participant was a mother with dependent children, the drive to care for the children superseded the need to seek relief from her aches and pains. One such middle-aged mother described how she refused an operation that could reduce her pain because it would interfere with her ability to care for her children:

> P: So far, that's all they've been able to offer is that operation, but they can't guarantee. And ah, [pause 3 sec], at the moment, I'm dealing with pain, but I'm still walking, I'm still able to take care of myself and my family…ah, [pause 3 sec] actually the chance of

> not being able to do any of that is ah, too big a chance for me. (P19)

Although surgery could have eased her particular condition, the participant was reluctant to pursue a treatment that might compromise her ability to care for her children. She, like other participants who were women caring for dependents, seemed fully prepared to subjugate their own suffering in order to ensure their children's needs were met. One participant suggested that this was a lesson taught intergenerationally to women in the community:

> P: I think that's ingrained. I think it's just a part of me. I don't know. That's the way my mum lived and that's the way my grandmother lived and my great grandmother and I've just seen these amazing women just never put themselves…above or before anything that their children might need, ever. So I don't know if it's… I don't know if that's a cultural belief, or it's a moral belief or… it's just so much a part of my DNA. (P21)

While most participants who were women described deriving great strength from this role, their narratives suggested that this perspective also put women at risk as they left their own pain and suffering unattended.

Similarly, the role of grandparent was also described by participants as influencing their ability to live well with their aches and pains. Both men and women described how being a grandparent helped keep them active. An example is this narrative provided by a woman in her fifties:

> P: I don't know if it'd be any different nowadays, like, from back when, like, if my son had moved out, um, I think in a way it [arthritis] might have progressed more, because it seems like since he stayed, and I got two grandsons, I'm doing more. And, my doctor says the best thing that I can do for this is to keep moving…picking things up, and just always trying to use your fingers, and that's what I do with my grandsons. (P11)

Many participants lived in households that included at least three generations. For those who were grandparents, living in this intergenerational context seemed to facilitate their ability to live well with their aches and pains. However, for some elder participants, particularly those who were parenting their grandchildren, family responsibilities created fatigue, which aggravated their aches and pains. Hence, although family relations were mostly viewed by participants as a resource for pain, narratives revealed that in the cases of parents who were women or elders, enacting the family role sometimes came at the cost of more pain.

The Role of Traditional Medicines

The narratives of participants revealed that orientations towards traditional medicines were diverse. Many participants stated that they did not use traditional medicines. For instance, one middle-aged man said “for me, traditional is to go to the doctor” (P06), even though he reported rarely seeking a doctor. Other participants shared stories that described some limited use of traditional medicines. Such was the case of this man in his fifties:

> P: I think the only time I do something like that though is uh, is like, when I start thinking in, you know, native. Like usually when I take that, I have a smudge and I put on uh my grandfather’s uh hand drum thing. Usually when I do that I go and lock my bedroom from there and I have the tea and put a candle on and, and then have, have my one little smudge eh. And then I put my grandfather’s drumming thing on and that’s, that’s not too, not too often eh. And it makes me feel better like when I get depressed eh, I listen to uh my grandfather and grandmother’s singing their hand drumming tunes. (P13)

While this participant noted that his use of traditional medicines helped him live well with his aches and pains, elsewhere in his narrative he also noted that his family members did not support his use of traditional ways of being well. This was a reflection of the fact that many First Nations communities are saturated with tensions between the *old ways* and modernity (Marker, personal communication, Dec., 2009). These tensions were revealed in the private conversations of community members, some of which I was privileged to be a part of. However, due to the sensitive nature of these conversations, I am aware that they belong to the community and are not appropriate for comment here. These tensions shed light on the complex position that traditional medicines have in this community. The relevant point for this discussion is that traditional medicines’ role in helping participants to live well with their aches and pains was varied and often limited. While a few participants engaged with traditional ways, many more did not, shaping a need to turn to the health system as a resource for health and healing.

The Role of the Health System in Living Well with Aches and Pains

As mentioned earlier, most, but not all, participants described a desire to avoid or at least delay encounters with the health system, whenever possible. For example, one man in his late forties noted that he’d have to be in severe pain before he would seek help from his doctor, “If I can’t walk anymore, then I’m going to the doctor [laughs]” (P10). This subsection explores participants’ actions and attitudes towards accessing the health system. I begin by exploring the concept of *subjugation of the physical*. The narratives of many participants seemed to reflect a marginalization of their physical self; I interpret this as resistance against a health system that prioritizes physical aspects of health such as the physical signs and symptoms of arthritis. Following, I discuss three themes that participants described as barriers to seeking healthcare: 1) health professionals do not care about them, 2) perceptions of racism and discrimination, and 3) the limited effectiveness of prescribed healthcare treatments. I end this subsection with a discussion of participants’ positive experiences with the health system.

Subjugation of the physical. The narratives of approximately half of the participants made reference to acts that seemed to harm or otherwise marginalize the physical body. These kinds of comments suggested an overall orientation that could be characterized as a *subjugation of the physical*; that is, the stories that many participants shared suggested a disregard for their physical self. For instance, some participants (mostly men) described their behaviour as “daredevil” or “self-destructive” in some cases. In other instances, participants described a lack of effort to take care of themselves. An example of this was a middle-aged woman who suggested that she did not take care of her body as much as she should:

> P: I’ve never really wanted to [talk to my doctor about my pain]. [laughs] I know I should so…
>
> R3: Why do you know you should?
>
> P: [pause 6 sec] Take care of my body [laughs]. (P02)

Many participants seemed somewhat unconcerned about safe-guarding their physical selves. Some engaged in activities that had a high likelihood of resulting in pain/injury. Others seemed prepared to live with bodily dysfunctions rather than actively seeking relief from them.

One participant, used here as a case example that differed from most other participants, explained his behaviour in this regard as a form of self-punishment. This man in his late thirties had engaged in illegal and illicit activities in the past and was feeling guilt about his prior life course:

> P: Yes, because I haven’t forgiven myself for all the stuff I’ve done in the past…because of all the stuff I’ve done to other people in the past, I don’t deserve to be happy or healthy, like I deserve the pain. It’s actually a form of self-punishment, not to do anything about it…I’ll probably be at the point pretty soon where [pause 2 secs] I stop punishing… when nobody else is…I’ve forgiven everybody, except myself. And I said, nobody else is punishing me except myself and if I can get to the point where I can forgive myself… [pause 2 secs] I’m starting to take care of myself a little bit better. I just haven’t dealt with the pain yet. [pause 2 secs] The physical part will come after I think. (P06)

This participant noted that the subjugation of his physical needs was linked with self-punishment and a lack of feelings of self-worth (Kirmayer et al., 2003).

However, the responses of many other participants suggested another interpretation of instances where participants seemed to disregard their physical bodies. A close examination of many responses revealed that participants seemed to disregard the needs of their physical bodies particularly when taking care of the body meant going to the doctor. For instance, this participant, a man in his late forties, noted that he did not seek healthcare for a wrist injury, which, according to his narrative, led to incomplete healing and eventually to arthritis:

> P: And, geez what was it, I wiped out one summer on my 10-speed. Instead of going and getting my wrists checked, eh, I just went and taped them up and continued riding around. A couple of weeks later, you can see all the stiffening up in both wrists, arthritis. So I never got that checked, should have. (P04)

This participant, like others, seemed to avoid getting his physical ailments treated by a doctor. He recounted a long list of injuries that he left medically unattended and hence failed to heal completely. As follows, many of these injuries continued to provoke pain. In most cases, a subjugation of the physical was linked with avoiding accessing healthcare.

Indeed, many participants seemed to be attending to their physical needs even though they were not actively seeking healthcare. For instance, the participant in the previous quote did take care of his wrist injuries, albeit perhaps incompletely. Further, this same man did much to care for his body. He described a rigorous and consistent pattern of physical activity: “making sure you stay in shape there, to deal with the pain” (P04). Hence, for most of the participants whose comments reflected a subjugation of the physical, subjugating acts were linked most often with resistance towards the health system.

“It’s like, to me…she doesn’t care.” The narratives of many participants included references to their doubts about their doctors’ genuine regard for their well-being. The common attitude of “my doctor doesn’t care” was related to past experiences where participants felt they had been dismissed by their doctors. The sense of doubt was also related to the rushed timeframe of most doctor appointments. Many participants felt that their doctors did not spend enough time with them to really understand them and what was going on in their lives. For most participants, these feeling contributed to their reluctance to seek help for their pain, as illustrated by the words of a middle-aged woman:

> P: [pause 3 sec] I don’t talk to her [doctor].
>
> R3: This is not the person in your life that you talk to.

> P: Nope. [laugh] No. You know, I never really thought of it like that…Now that you mention it, you know, I'm not about, um, about my doctor, it's like, to me, it's she doesn't care. So that's why I don't want to go back to her. (P02)

Like other participants, the woman who made the above comments did not seek a new doctor. However, she limited her access to this resource and did not expect much when she had an encounter. Many participants choose to remain with their doctor despite their descriptions of less than optimal care. In some cases, participants stayed because they had had difficulty finding any doctor related to a regional shortage of general practitioners. Others stayed with a doctor they were familiar with because the option of starting over, which included retelling their personal story, was not appealing.

Not all participants choose to stay with a doctor that, to them, projected a lack of caring. A few participants talked about their search to find a better doctor. In most of these instances, participants talked about being more satisfied with the care of their newer doctor. One example was an elder woman who searched for a doctor who would believe her reports of relentless and widespread pain for which she was seeking a disability claim. She reported many disappointing experiences in her search, which left her frustrated and angry. "Like, some of these doctors really must think we're quacks, you know? We have nothing better to do than sit at home and make up your aches and pains?" (P17). The difficulty that many people, with ongoing diffuse pain, have in being believed by health professionals is well-documented in the chronic pain literature (e.g. Craig, 2009). However, in the context of this participant, not being believed intersected with other negative experiences, including experiences of perceived racism and discrimination (discussed in the following subsection). Together these experiences created a web of discomfort that acted as a barrier between many participants and their physicians.

Negative experiences in the health system. Stories that included accounts of perceived racism and discrimination while accessing healthcare were told by nearly every participant. These experiences were remembered and vividly recounted, and contributed to a feeling that the health system was not necessarily a safe place to go. This was the theme of one elders' meeting I attended where several elders reported that local doctors had told them they were "too fat" or "too complicated" for their practice. In some cases, elders reported walking out on a first doctor visit when the doctor seemed to focus solely on their weight. These reports are, of course, self-reports and yet it was clear that these were the messages heard by these elders. Indeed, these elders reported that they were always "looking for signs of racism" in encounters with healthcare professionals who were new to them. Similar finding were reported by Browne and colleagues (2010); people who have experienced previous incidences of perceived racism/discrimination can become especially attuned to the racializing actions of healthcare professionals.

Most participants described their sense that health professionals often see them through the lens of commonly-held negative stereotypes. For example, this man in his fifties tells a story of accessing a local emergency room for incapacitating back pain:

> P: "[I overheard a nurse say to a doctor] 'A patient's in there with a bad back' [meaning the participant],…I heard them say something like 'Oh, they're all wimps, just give him some of this.' And I was going to say, 'Hey, I can hear you, you knucklehead.'" (P12)

In this example, the participant reported that he felt healthcare providers were viewing him as *drug-seeking* (Koptie & Wesley-Esquimaux, 2009). Several participants similarly reported that many health professionals would automatically view them as being prone to substance use and/or alcoholism (Browne et al., 2011; Kelm, 1998; Tang & Browne, 2008). For instance, one participant (P24) noted that when he presented to a medical clinic or emergency room with an unsteady gait related to his pain, the first question asked by health professionals was always

"How much have you had to drink?" The fact that many participants reported these kinds of interactions with healthcare professionals supports the claim that racializing discourses about Aboriginal peoples are active and commonplace in the healthcare context (Browne et al; Tang & Browne).

Some participants described stories in which the racializing practices of healthcare professionals resulted in ineffective care. One participant remarked that she became so distressed by remarks from her physician, which to her reflected racism, that she was unable to communicate her health issues. Other participants noted that they would simply leave the healthcare encounter when faced with remarks they perceived to be racist. These kinds of encounters were experienced as profoundly negative by participants and left a lasting impact on their ability to feel safe with the health system, contributing to the notion that accessing the system carried the potential for harm.

"There isn't anything we can really do." Participants also described previous experiences with the health system where they had been unsuccessful at obtaining useful help. In particular, some participants noted that their doctors most often suggested a medication as the solution for a health complaint despite voicing an aversion to taking medications to their doctors. For instance, in the following excerpt I asked a middle-aged participant about her use of anti-inflammatory medications for her ongoing shoulder pain; she was clear that taking medications was not one of the options she considered for pain control:

> R: Have you tried that? Would you consider that?
>
> P: Nope. Nope. I wouldn't.
>
> R: You're not interested. Is it the pills you're not interested in or what's…
>
> P: I'm not interested in taking pills. (P02)

For this participant, her aversion to taking medications contributed to her reluctance to seek healthcare. She felt that since her physician had only medications to offer, and since she was not willing to take pills, she saw little utility in seeking healthcare.

In the context of a health system in which medications are a primary tool, participants' dislike of medications was a significant deterrent to seeking healthcare. As I sought to understand this dislike, one elder woman offered the following perspective:

> P:…I think it had to do with when I was in residential school, and they were giving me those sulpha pills. I hated swallowing those darn things. They tasted awful…And then they didn't give us very much liquids to wash them down…I had to take those darn things for almost... the whole month of January, February, March, April... four months. And I was taking those things, I don't know how many times, three, four times a day. I hate taking pills, anything that looks like a pill. (P03)

In this excerpt, the elder connected her dislike of medications to unpleasant experiences in residential school. Here again, the past is present in the current, historical issues and past traumas are operational in everyday life experiences.

For other participants, an avoidance of taking medications was more specifically tied to analgesics, particularly narcotics. This was especially true for participants that had struggled with substance use and addictions in the past. Most of these participants noted that they were "not allowed" to take narcotics for their persistent pain, even in cases where their previous substance use issues had not been related to narcotics. In some cases, it was their doctor who dictated this prohibition; in other cases, it seemed more self-imposed. Several participants noted that they either avoided taking narcotics all together or they limited their narcotic intake to instances when their pain fully incapacitated them. For instance, one man in his fifties, who had struggled with an alcohol addiction in the past, noted that while he was given a prescription for Tylenol #3s[33]

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[33] Tylenol #3 is a narcotic analgesic combination with acetaminophen.

(T3s), he seldom took the drug. “I just don’t use it [T3s] that much…I’ll get addicted again…” (P15). This participant linked his decision to limit his narcotic intake with a fear of addiction. His fear of addiction to opioids was fueled by a number of things: 1) his previous struggles with addiction; 2) opioid phobia (discussed in Chapter Two), which refers to a fear of addiction amongst both healthcare professionals and lay people, even though actual rates of addiction are quite low (Nobel et al., 2010); and 3) discourses, discussed above, that position Aboriginal peoples as particularly susceptible to addictions. While the participant in the previous excerpt did receive a prescription for a narcotic, often the most effective analgesics for moderate to severe ongoing pain (Nobel et al.), many others noted that their physicians were extremely reluctant to prescribe narcotics, even in cases where the participant had no previous experience with addiction. In the healthcare context where discourses that position Aboriginal peoples as *drug seeking* or prone to addiction are strong, healthcare professionals who lack the training to approach these discourses critically may be especially reluctant to prescribe opioids to Aboriginal patients. As a result, Aboriginal peoples experiencing chronic pain are at high risk of having their pain delegitimized and of being excluded from accessing the most effective analgesics (Browne et al, 2010).

Counter to societal discourses, taken up in healthcare contexts, that Aboriginal peoples are more prone to addictions and likely to be drug-seeking (Browne et al., 2011; Furniss, 1999), in this study the vast majority of participants were actively refusing narcotics for their pain. For example, in the following excerpt, a woman in her thirties noted that she did not bother talking to her physician about pain because she knew what his response would be; even though she had not struggled with addictions, her doctor’s perspective confirmed her own orientation towards narcotics:

> P: I don’t even bother talking to them about it. I’ve been thinking actually about going and talking to them about it again, but most of the time they just say, “There isn’t anything we can really do.” And, “We can give you pain killers, but you’ll get addicted to them, so what’s the point of that?” And that’s about as far as it goes, ever. So there doesn’t appear to be much point. (P19)

This excerpt points to the complexities that are behind the decisions of participants around pain control medications. The perspectives of the patient and the provider intersect and are mutually reinforcing. For those participants that excluded themselves from taking narcotics, a visit to the doctor for pain control was seen as being futile. Indeed, some participants reported seeking help from their doctor regularly for some other issues, while rarely seeing them for complaints of pain. For other participants, this orientation towards prescription analgesics seemed to spread to other medications; these participants were reluctant to take any medications and as a result, often failed to see the purpose of seeing their doctors for any reason.

A reluctance to seek care from a general practitioner has important implications for community members’ access to the entire system because of the general practitioner’s role as a gatekeeper to the system. Hence, people who were reluctant to access their doctors had fewer opportunities to access the rest of the system, in particular specialists, accounting perhaps for the lower rates of specialist referral for First Nations arthritics reported in the literature (Barnabe et al., 2008). They were more likely to “just deal with it” outside of the health system.

“I can talk to her…” While the majority of participants spoke about a reluctance to seek help from the health system, particularly for pain-related concerns, a few participants were not reluctant. These participants shared positive experiences they had had with their healthcare providers. A case in point was one elder woman who had a long history of diagnosed arthritis and many other medical conditions. She regularly sought advice from her doctors and attributed her success in living well with her conditions to carefully following her doctors’ advice:

> P: I have seen a lot of doctors…the one main thing that they have told me, right from the beginning that I was told I have arthritis was…walk, exercise…if I didn't do all this, they would know, they can tell in my walking…I listened to the doctor and she says, "I can see that." (P09)

This participant put great faith in her doctors, related to the thorough and sensitive care that she received:

> P: Like, she asks me questions and I tell her, or otherwise I say, oh, you know, this happened to me and I said, what am I supposed to do? And she checks all my, you know, my lumps and everything, checks my back and sees how my body is doing...I can talk to her about [things] and she will, you know, really want to know how it happened, when it happened, how long. You know, she sits there and writes everything down. (P09)

In addition to feeling safe and well-cared for, a subtext of her narrative was that she feared losing control over her body. Entrusting her body to her doctor, then, was a way to ensure that she would not "lose everything." In her comments above, she noted the fear of losing her ability to walk related to her arthritis and below, she references her diabetes. She was comfortable to entrust her body to medical professionals because she had had many positive experiences.

> P: 'Cause all my doctors have to work with diabetics, yeah. Because of ah, I can lose all my teeth, I can, you know, lose my toes, my feet, because of not taking care of them. Everything, I can lose my kidneys, my liver, everything, I can lose it. I can just… it'll just take over, yeah… (P09)

For this woman, and a few other participants, doctors offered an opportunity to protect themselves from further losses, perhaps related to the context of multiple losses, as discussed in the previous chapter. Key factors that seemed to facilitate participants' use of the health system were: 1) participants felt their doctors took the time to listen to their concerns, 2) advice and guidance had been useful in the past, and 3) participants felt safe and respected in interactions with healthcare professionals. While these three factors contributed to participants' comfort with the health system, as I discuss in the following chapter, these processes are not well-promoted within the structures of the arthritis services system.

Summary

The words that participants used and the ways in which they talked about their pain and suffering reflected the lessons they had learned in a lifetime of attempting to live well with their ongoing aches and pains. Participants' narratives and immersion experiences highlighted the theme *suffer in silence.* This theme shaped the way that participants used the three main resources for health and healing: the family, traditional medicines, and the health system. Most participants used all three systems to a greater or lesser degree, although their use was often limited by the constraints imposed by the community norm of suffering in silence.

Many participants spoke of reluctance to use the health system. Many questioned the benefit of seeing a doctor. This was linked to past experiences where doctors had dismissed them outright or had only medications to offer. In making decisions to access healthcare, potential benefits were weighed against potential risk for harm, including potential exposure to racializing or discriminatory practices. Incidences of perceived racism and discrimination combined with perceived incidences of being dismissed/not helped, contributing to a reluctance to seek healthcare. In cases where past negative encounters were forefront on participants' minds, reluctance to seek healthcare was magnified. However, in the few cases where participants recalled many positive experiences, use of the health system was not limited. This analysis shows that although many participants were reluctant users of the health system, under the right conditions, participants benefited from accessing healthcare. The current organization and delivery of healthcare influences the conditions under which healthcare is provided. These conditions are discussed in the following chapter.

CHAPTER SEVEN: ARTHRITIS HEALTH SERVICES

In this chapter I review the findings that explore the organization and delivery of arthritis health services. I consider these findings in light of the findings presented in earlier chapters in order to examine how well-aligned arthritis services are with the experiences of arthritis of community members. I begin this chapter by discussing the experiences and perspectives of healthcare provider (HCP) participants in providing care to patients who are Aboriginal. Their narratives revealed the influence of *rationing, biomedical, self-management, and culturalist* discourses on their practice. In the second section of this chapter I discuss the findings related to the organization of arthritis services. I discuss the overall organization of services, as well as the services that are being developed specifically for Aboriginal populations. Although initiatives to improve arthritis services for Aboriginal peoples were underway, the analysis provided here suggested that the changes were unlikely to substantially affect Aboriginal peoples' experiences of pain and suffering because both new and long-standing services are not well-aligned with experiences of arthritis as discussed in this dissertation. However, the willingness of both HCPs and decision-makers to engage with new knowledge suggests that there is good potential for arthritis services to become better aligned with the arthritis experiences of First Nations peoples.

Providing Services to Aboriginal Patients: Arthritis Providers' Perceptions

In this section I discuss the three main findings that shaped how healthcare providers deliver arthritis care: a) HCP were aware of the complex social circumstances that influenced both arthritis and utilization of healthcare for some Aboriginal patients but they were constrained in their ability to respond to these circumstances; b) HCPs, influenced by wider social discourses, tended to frame Aboriginal patients as passive; and, c) negotiating Non-Insured Health Benefits (NIHB), as a resource that ostensibly could have been of benefit to people with

Status, was most often a source of significant frustration as procedures to access benefits were complex and many submitted claims were denied.

Addressing Complex Social Circumstances in the Midst of Rationing and Biomedical Discourses

Almost every health professional interviewed for this study showed obvious and sincere concern for the Aboriginal patients that they encountered. Most acknowledged that many of the Aboriginal patients they encountered lived with complex social conditions that influenced their arthritis. This nurse articulated an example based on her experiences of a patient's complex social situation:

> HCP: I am trying to think of this one woman in particular. She was First Nations. She had lupus[34]. She had four children...it was impossible for her to bring her children here…and be here for the time that she needed to be… So, you know, she frequently didn't come to her appointments, or she'd come to her appointment and then if she had to wait for longer than 15 or 20 minutes, she would have to leave and miss her appointment…So her disease, like, wasn't being managed properly, um… because she didn't have access to the physician when she was available to see the physician… She had to travel from a distance… and she had to get rides, she didn't have a car… and she had multiple socioeconomic issues layered on top of this terrible disease, and those were her priorities but we sort of tended to focus on her disease…She really had a need to…address all these other things that were going on in her life. Like she had an abusive husband… (HCP03)

This HCP demonstrated a broad understanding of the context of this woman's life. She, like some other HCP-participants, noted how complex social circumstances can impede patients' abilities to access care. Many HCPs noted that some Aboriginal patients have difficulty attending all appointments. Most also acknowledged that, as healthcare professionals, they ignored the "three missed appointments and you're discharged" rule, creating some flexibility in the arthritis services context for patients they perceived to be compromised in their ability to access care.

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[34] Lupus is one of the many diseases that is sometimes, but not always, considered under the catchment of arthritis.

Where HCPs felt they were able to bend the rules, they did so for the benefit of Aboriginal patients.

In other situations, HCPs felt less able to “bend the rules” to account for complex social circumstances. This was particularly true for HCPs working in outpatient settings where tightly scheduled patient appointments structured their days. These HCPs tended to voice concerns about the time pressures of their job. Because of these pressures, HCPs made difficult decisions about what they would focus on during their limited time with a patient:

> HCP: Yeah, yeah, there’s lots there in the background, and I don’t even go there. I know if I go there, I’m not going to get him... You see, I have to get him in and out with, within a certain amount of time. (HCP11)

As this HCP noted, time constraints heavily influenced her decision to put biomedical issues in the foreground and social issues in the background. She prioritized her care to focus on what she perceived to be most important within the time allotted to her. Many narratives reflected HCPs’ frustration as they struggled to provide services in the time that was allotted. These kinds of comments reflect the pervasiveness of rationing discourses in the arthritis services context; within this context, HCPs prioritized biomedical issues and often left social issues unaddressed.

While this approach was effective because it ensured that HCPs could see all the patients scheduled for a particular day, other HCPs noted that rationing care in this way was problematic because unattended complex social circumstances often contributed to a need for readmission:

> HCP: Oh, and that's another thing we find, right, the reason why we have people… coming in from home every couple of years, isn't, isn't so much because their arthritis has changed. It's more because there are reasons why they're not managing that are not physical. So I think you can't necessarily, if you're really going to look at the issues and really look at interventions, you can't look at arthritis specific um, interventions, like, alone. (HCPgrp2)

The above comments were provided by a HCP working in the inpatient setting, which allowed more flexibility in the time HCPs could spend with patients who were often admitted for four to six weeks or more. Hence, arthritis setting differed somewhat in the degree to which professionals could move beyond biomedical issues. In the arthritis settings where rationing discourses/time pressures were stronger (i.e. in the outpatient settings), biomedical discourses seemed also to be stronger. Nonetheless, even in the inpatient setting, most HCPs reported that they were only marginally able to address the complex circumstances of some Aboriginal patients. While some HCPs identified that attending to issues, beyond just the physical issues, should be a key component of care, for the most part, they acknowledged that the arthritis services system is currently not set up to do so.

Most HCPs demonstrated an understanding of how the social determinants of health influenced the experiences of arthritis of some Aboriginal patients. However, these understandings were not readily translatable into their practices, a shortcoming that is common in healthcare systems (Farmer et al., 2006). As a result, most participants acknowledged that arthritis care for Aboriginal peoples was not optimal. Several HCPs, like this nurse, spoke with frustration about the current system, which seemed unresponsive to the complex social circumstances of many Aboriginal patients:

> HCP: Well, it's… it's, "We're here. This is what the… service we provide. So you come to us, and this is how we want you to come to us, and there's only one path that you can take. And if that path doesn't fit with your... whatever is going on in your life, then too bad. You don't get our service." (HCP03)

Constructing Patients as "Passive": Culturalism and Self-management Discourses

Nearly every HCP interviewed commented that most of the First Nations patients they encountered were "passive." Given that the perspectives of healthcare professionals are often shaped by discourses dominant in healthcare and in the wider social world (Browne, 2005), HCPs' repeated use of the specific term passive suggests the influence of self-management discourses, which frame active (not passive) patient behaviour as the appropriate response to chronic illness. Further, as I show below, the ways that HCPs made sense of the so-called passive behaviour reflects the influence of culturalist discourses.

The passive behaviour of First Nations patients was qualified by HCPs as, for example, being not forthcoming in conversation, complaints, and decisions made about medication adherence, and/or as not pursuing recommended follow-up after discharge from arthritis services. This nurse described a trait she perceived to be common among First Nations patients, being unable/unwilling to initiate help-seeking through the health system:

> HCP: …it's just getting them to take any initiative on their own, I mean that's the one I struggle with I think the most is getting them to take some kind of initiative and just following through, and picking up the phone and calling their GP, or going there. (HCP17)

This HCP, like many others, suggested that patients ought to be in control of their health and their healthcare as evidenced by being active in directing their care. As such, patients who were reluctant to actively engage HCPs (for a variety of reasons, as discussed in Chapter Six) were often seen by HCPs as passive.

The perspectives of HCPs were aligned with self-management discourses, which emphasize individual responsibility for health; patients are expected to take control of their health/illness and manage it effectively (Redman, 2009), to be active (as in the CCM- "informed activated patient") not passive. The pervasiveness of self-management discourses in the arthritis services context was notable in that most HCP-participants made some reference to it within their narrative. Indeed, one HCP noted that the health system has adopted self-management training as the primary response to the burden of chronic illness: "self-management…chronic disease self-management is, still seems to be the focus of panacea for chronic disease [laughs]" (HCP12). The predominance of self-management discourses in the arthritis services context created expectations amongst HCPs that patients ought to be "activated" and fully engaged with

HCPs; patients who were not so engaged were labeled as passive. It is not surprising that self-management discourses are entrenched in this service area since the self-management movement originated in the arthritis field and has been promoted within it for the past 30 years (see Chapter Two).

Some HCP participants discussed what they understood to be the impact, in terms of the care provided, of "passive" behaviour. The following narrative was provided by a rheumatologist who provided outreach services to some rural and remote communities:

> HCP: And you know, I would say the patients are…not particularly demanding. So if you tell them they can't have this or that, it's all just cool. You know, and that's... So that's a reason, if they're not ah... I mean, they could have more than they are getting – I mean they're getting pretty good – but you know, they fall behind also because they don't demand. (HCP11)

This physician noted that there were service implications for patients who did not demand services: Patients needed to be strong advocates for themselves in order to get the most out of the system. The predominance of self-management discourses in the arthritis services field shaped the way services were provided; patients who lacked the resources required to successfully negotiate the arthritis system "fell behind" in terms of the services they received.

HCPs tended to explain passive behaviour as a cultural trait inherent to Aboriginal peoples. Browne (2005) similarly found that nurses tended to view quietness or reticence as a cultural trait. At the same time, Browne found that nurses were largely unaware of the ways in which historical circumstances and current power dynamics could be contributing to the behaviour encountered. Such interpretations reflect the influence of culturalist discourses in the arthritis services setting and in healthcare settings more widely.

Reflecting a culturalist orientation, the subtext of many HCP narratives suggested that Aboriginal patients were often viewed as cultural Other. As follows, HCPs made repeated references to the need for HCPs to better understand the culture of Aboriginal peoples in order to provide adequate care. An example is this rheumatologist:

> HCP: Well, I think at the individual level all the healthcare professionals have to have an approach that, um, adapts itself to the culture of the clients or patients that we're dealing with. So that's at an individual level, at a system-based level, um, I think well, [pause 5 seconds] I'm trying to think. You know delivering culturally appropriate care. (HCP13)

While becoming familiar with a patient's culture is an important part of good care, narrow conceptualizations of culture (as have been promoted in healthcare over the past decades, see Chapter Two), as being static and divorced from the social, political and historical context, leave critical aspects of the patients' life unexamined (Browne, Varcoe et al., 2009).

Healthcare professionals' interpretation of passive behaviour as a cultural trait influenced the solutions they implemented in attempts to work with Aboriginal patients whom they perceived to be difficult to engage. A key strategy reported by many HCPs was increased time for communicating with Aboriginal patients, creating some increased tensions for HCPs who were operating in highly time pressured environments. Good communication was seen as the way to bridge the "cultural barriers" (HCPgrp2). While effective communication is undoubtedly critical in the provision of effective care (e.g. Doane & Varcoe, 2005; Whitty-Rogers, Etowa, & Evans, 2006), such strategies leave unattended unequal power dynamics that may be complicating healthcare encounters (O'Neil, 1998).

While most HCPs talked about the culture of Aboriginal peoples in ways that were congruent with a narrow conceptualization of the term, the narratives of a few HCPs, for instance this OT, demonstrated a more critical view of culture and the reasons that some First Nations patients may not fully engage with HCPs:

> HCP:…well, I think as health professionals and people that work with First Nations, we have a responsibility to be aware of what… to be culturally aware of who we're dealing with. And First Nations have… you know, a special background with the residential

> schools, and colonialism and, um… all those issues. And I think we have a responsibility to understand why, maybe, First Nations people don't engage in the same way with the health care system as we've set it up… uh… than other groups. (HCP08)

Elsewhere in this narrative, this HCP acknowledged that she had been unaware of the influence of the history of First Nations people in Canada on their health and healthcare utilization until she had heard me speak on the topic at an ongoing education session. Her ability to integrate this new knowledge into her understanding of the experiences First Nations patients points to an important potential for the translation of critical social knowledge into arthritis services settings.

Dealing with Non-Insured Health Benefits

A key target for the frustrations of HCPs was NIHB. Although NIHB was developed to be a resource to help "eligible First Nations…reach an overall health status on par with other Canadians" (Health Canada, 2003b), the data from this study revealed an ever-dwindling list of items that were covered and a system of accessing coverage that was so mired in red tape that many eligible First Nations individuals went without medications, medical products, and other services.

A key frustration discussed by several HCP participants was the removal of items from the allowable benefits list. This had serious implications for patients who could not afford the ineligible items. HCPs repeatedly described the decision to remove particular items as illogical. For instance, one nurse noted that expensive nutritional supplements were not covered for a woman whose emaciated status, if not addressed, would make the need for the covered arthritis medications redundant. Another commented on the futility of providing foot orthotics for patients if they did not have appropriate shoes to make the orthotics functional:

> HCP: They [NIHB] used to provide support shoes, like running shoes. That was great, because especially for people in communities with unpaved roads, and walking on [them] is challenging anyway, and then you have bad feet and bad ankles, you really need the shoes…But it's almost like giving a splint without any straps. If you don't have a good

> pair of shoes to put the orthotics in, they're just slipping around…they need the supportive shoes to hold the orthotics in place and do the job properly. (HCPgrp1)

Hence, NIHB's shrinking list had more impact than was immediately visible. Not only were some things no longer covered (and hence not accessible for many people) but those that were covered were rendered less effective because more basic items, that supported and enabled the covered items, were not available. The financial constraints experienced by many First Nations peoples meant that items that were not covered were usually not obtained.

A second frustration was the complicated protocols and procedures that were required by NIHB in order to obtain coverage. An example of the complicated process was given by one HCP who worked in the First Nations community that was the setting for this study:

> HCP: Then you have to go to your doctor… or first of all…pharmacy will fill out… an exemption form, send it to Non-Insured Health Benefits…see if they'll cover it for that client. If not, then another appeal form has to be filled out and then it goes to the doctor, goes to Non-Insured Health Benefits, goes to a drug exception centre, then goes back to the pharmacy…The second step takes a lot longer. You need letters from the doctor, you need a letter from the pharmacist, it goes to Non-Insured Health Benefits "drug exception centre" then goes back…For four to six weeks, they're not taking the meds. (HCP14)

This participant noted the many steps required for a drug that wasn't automatically covered for all individuals who qualified as status First Nations. Many analgesics (especially narcotics), some anti-inflammatories, and many arthritis disease-modifying drugs were not automatically covered; hence people with arthritis commonly had their prescriptions embedded in these approval procedures. HCPs were concerned about the time and effort that was required to meet NIHB standards and acknowledged that as requests for coverage were stalled in the complicated processes, the First Nations patient went without the needed item.

In their narratives, many HCP complained about the lack of feedback they received from NIHB regarding their requests for coverage, particularly when claims were rejected. Some said that they were sometimes not even made aware of a rejection until weeks or months later. Hence, many HCPs, like the rheumatologist featured in the quote below, made reference to the "Black Hole" of NIHB:

> HCP: I've had some horrible scenarios with them where, you know… the patient was on Humira [a drug for RA], was doing well, ran out of her… first three month course and um, needed a renewal. Um, it took her six months to get her… back on the drug…She was off for six months and it was just [pause 2 sec]…they [NIHB] were not communicating well with me. Uh, I would ask them, what's the problem, and I would [get no response.] (HCP11)

Many HCPs noted that they had trouble filling out the complicated forms and many acknowledged that their own mistakes in the paperwork had been a factor in denied claims. As such, they were eager to correct the mistakes. However, direction from NIHB about where the mistake was and how to correct it was often missing. Since the efficacy of most of the newer disease-modifying drugs depended on administration early in the disease trajectory, these kinds of delays had a serious potential to contribute to poorer outcomes in status First Nations patients with RA.

Other HCPs, particularly physiotherapists (PTs) and occupational therapists (OTs), noted that a significant contributor to the time delay in patients receiving prescribed equipment was in obtaining a physician's signature:

> HCP: Um, just there's lots of paperwork… NIHB requires the physician's prescription. Whereas um, the Ministry doesn't…I'm able to prescribe equipment and orthotics for MHR [B.C. Ministry of Health Services]. So the doctor's only here once or twice a week… I have to make sure I've got that doctor's prescription, which sometimes can delay things by a week because I need to wait for the doctor to come in. (HCP grp2)

The need for a physician's signature frustrated OTs and PTs, not just because of the time delay for patients but also because they interpreted it as undermining their authority since such signatures were not required for similar equipment requests for patients funded through other third party funders, such as the B.C. Ministry of Health Services or the Worker's Compensation Board of British Columbia. Their belief that NIHB was reinscribing medical authority was compounded by the fact that NIHB would cover patient travel expenses for a medical appointment but not for an OT or PT appointment.

A few HCPs, who had significant exposure to NIHB, were satisfied with NIHB as a resource for those patients who were eligible, suggesting that success in navigating NIHB is contingent upon having considerable experience negotiating the processes. However, even these HCPs noted that improvements were warranted. NIHB's policies and procedures seemed to be going against the efforts to improve the health of First Nations peoples. Fiscal constraints and bureaucratic requirements meant that NIHB practices were not well-aligned with the experiences of First Nations individuals with arthritis.

The Structure of Arthritis Services

The analysis of the structures of arthritis services was based primarily on immersion experiences in institutions that provided arthritis services as captured in detailed fieldnotes. Interviews from participants also provided some contextual information. In this section, I begin by describing the unofficial arthritis hierarchy, which structured specialty arthritis services so that services for RA (and other inflammatory conditions) were prioritized over services for OA and FM. Decisions about what kinds of services were prioritized were influenced by forces that drive the current organization of services, such as cost-effectiveness concerns. Despite these constraining forces, specific services for some Aboriginal populations with arthritis have been developed. However, because of their emphasis on technological and biomedical solutions, they were not well aligned with community needs. Even those programs specifically designed for First Nations peoples may have had little impact since they did not target the most pressing issues that contributed to the pain and suffering of First Nations individuals with arthritis. However, arthritis service decision-makers' continued desire to enhance services for Aboriginal peoples suggests a potential to improve the alignment of services with the arthritis experiences of First Nations people.

The Arthritis Services Hierarchy

The analysis of fieldnotes and HCP interviews demonstrated that some types of arthritis were prioritized, in relation to resource allocation and services, while others were marginalized. Specifically, the bulk of specialty arthritis services were accessible only to persons who received a diagnosis of inflammatory arthritis, particularly RA (as the most common form of inflammatory arthritis). People with OA were assumed to be able to get their needs met through primary care and people with FM were marginalized and stigmatized and offered primarily psychiatrist interventions. This created several issues in relation to the provision of arthritis healthcare to First Nations peoples: 1) First Nations individuals with arthritis were disadvantaged in obtaining a diagnosis of RA because current diagnostic criteria was based on a European middle-class norm; 2) The majority of people with arthritis, who have OA, were excluded from accessing interdisciplinary care; and, 3) the existence of FM in First Nations communities, and its complex roots, went unacknowledged and appreciated.

Problems diagnosing rheumatoid arthritis in Aboriginal populations. Diagnosing RA in First Nations peoples may be problematic, as I discovered while participating in a research symposium on arthritis in North American indigenous populations. Research and opinion leaders attending the symposium noted that many Aboriginal individuals with arthritis presented with complex symptoms that reflected several types of arthritis, but no one type completely. These leaders noted that because the current diagnostic criteria had been based on a European middle-class norm, it probably lacked the ability to adequately discriminate between types of arthritis in Aboriginal populations:

> We know that the phenotypes of INA [Indigenous North American] populations are different from the general population, therefore we cannot rely on the accuracy of our current system of disease definition and classification. We need to explore changes to the current American College of Rheumatology guidelines… (Centre for Aboriginal Health Research, 2009)

First Nations individuals with arthritis did not always fit neatly into the diagnostic system that drew tight boundaries around the types of arthritis. As such, First Nations individuals would be less likely to receive a diagnosis of RA, without which they would be ineligible for the bulk of specialty arthritis services.

Positioning osteoarthritis as appropriate for primary care. According to program planners, inflammatory arthritis/RA was prioritized because of its severity, pathogenesis, and the consequential need for interdisciplinary care. Conversely, OA was not prioritized because it was assumed that OA could be readily cared for in the primary care context. For example, one rheumatologist stated: “The trouble is, if it’s OA, most GP’s are pretty capable. If it’s inflammatory arthritis…their ability to diagnose…is poor and their ability to provide treatment [is] pretty poor as well” (HCP11). However, other HCPs, as well as literature reviewed earlier, suggested that OA is not managed well in primary care. As one HCP suggested, “Primary healthcare should be able to manage OA…Now, I don’t think we’ve demonstrated that we can [laughs]” (HCP12). Indeed, the complicated and significant pain and disability experienced by community participants in this study, who experienced a variety of types of arthritis, suggested that interdisciplinary management was often required for any type of arthritis.

The decision to exclude individuals with OA from most specialty services was made in response to rationing discourses. For example in the excerpt below, the HCP noted that occupational services for OA were stopped because of fiscal shortfalls and the corresponding need to manage waitlists:

> HCP: Yeah, and that was a function of our waitlist for service and the fact that the focus for us, umm, just has to always be inflammatory arthritis…because of the chronic and remitting disease, because of, of the multiple joint involvement…I guess we have to look at, are there alternative ways that people can be served that are as effective?...with Occupational Therapy, we were just so backlogged on our, on our inflammatory referrals…the team really did an internal process and said, "Well, which of the groups that are waiting so long for us, could be served differently?"… It's probably, you know, as good as we can do in this situation… (HCP12)

The limiting of specialty services to people with RA created some gaps in services, since the majority of people with arthritis have OA (Health Canada, 2003a). This was true within Aboriginal populations as well (FNC, 2005). I draw on an example from a community participant to illustrate the impact of the gap in service. One elder reported that she had received excellent interdisciplinary care, from arthritis services, for her complex OA many years ago. More recently, when she tried to access arthritis services for updated assessment and care, she was told she was no longer eligible for services given her diagnosis. Although this elder did receive some advice about where she could access services for a new pair of orthotics (one of the services she was looking for), she did not follow-up on this advice, having no skills or resources to negotiate unfamiliar commercial venues. Hence, the move to delist OA as a diagnosis of priority created a gap in service for First Nations peoples who had complex OA related to the histories of hardship that have contributed to their condition. While they may have been equally severe in their presentation of need (i.e. chronic and remitting disease with multiple joint involvement), without an inflammatory diagnosis they were ineligible for interdisciplinary care.

Marginalizing people with fibromyalgia. While people with OA were excluded by the arthritis hierarchy, because they were assumed to have an "easy to manage" disease, people with Fibromyalgia (FM) were further marginalized because they were assumed to have a largely psychosomatic, rather than a *real* condition (Clark, 1999; Gagliese & Katz, 2000). For instance, my analysis of fieldnotes from ongoing HCP education lectures on the topic of FM recount how people with FM were repeatedly positioned as “difficult to work with” because of their “difficult personalities” (i.e. people with FM often had co-morbid psychological symptoms that reflected emotional distress, such as anxiety, depression, and post-traumatic stress disorder and they were often assumed to be malingering or overly sensitive to pain). As a solution to the perceived problem of providing care to people with FM, a psychiatry service was proposed and initiated, reinforcing the view that FM is a psychiatric not a biomedical condition. While only two community participants had received a diagnosis of FM (in one case it was an FM-like condition), the strong association between trauma, long-standing pain, and FM (Amir et al., 1997; Campbell & Edwards, 2009; Edwards et al., 2006; Roy-Byrne, Smith, Goldberg, Afari, & Buchwald, 2004; Sharp, 2004) suggests that this might be a fairly common type of arthritis in Aboriginal populations. However, because FM patients were believed to be difficult to work with, many rheumatologists were reluctant care providers for this population.

Even though OA and FM were probably much more common than RA in First Nations communities, only the diagnosis of inflammatory arthritis (usually RA) ensured access to the bulk of specialty services. Hence, the majority of community participants would not qualify for specialty arthritis services.

Prioritizing Services: Specialist and Cost-effective Services

Within the arthritis services settings, specialist care and services deemed “cost-effective” through research were prioritized, reflecting the continued influence of biomedical and rationing discourses (Baum et al., 2009). For example, this decision-maker, when given a hypothetical magic wand to improve arthritis services, suggested that not many changes were warranted, except perhaps more specialists:

> HCP: Well, I can’t see ah, even with a magic wand, ah, changing [the services provided] that hugely. I mean [pause 2 sec], just ah... I mean, of course we need more

> rheumatologists. So if the magic wand could get us more medical students and more rheumatologists that'd be good. (HCPwithheld)

In my many informal conversations with decision-makers, biomedical (e.g. medication clinics) and specialist care was repeatedly positioned as non-negotiable in terms of being considered for reductions in service. Conversely, as noted by this decision-maker, services that could potentially help people with arthritis manage complex social situations were typically positioned as extras that the system could not afford:

> HCP: Well, I mean it would be a nicety, yes; it would be a nicety to do that. Um, could the centre offer those services, it makes it really difficult, ah, you know, with everybody up to their eyeballs in all the programs. (HCP13)

In the context of fiscal restraints and rationing discourses decisions about service priorities needed to be made. In the arthritis services setting, decisions seemed to be influenced by biomedical discourses that positioned highly technical care, focused on biomedical processes, as foundational to arthritis services.

However, not all HCPs were comfortable with these kinds of decisions. Some advocated strongly for a more holistic approach to services. A few HCPs, who had been long-time employees, were frustrated at the slow pace of change within arthritis services, particularly in enhancing services to address the social issues of patients. The following excerpt reflects the content and tone of many of these conversations:

> HCP: We're constantly asked for our input and our feedback on this, that, and the other thing… but nothing changes. Like, there's something fundamentally just hard-wired into the system where nothing changes… Things still get imposed from the top down, and there's definitely a chain of command and… you feel like you're just sort of on the front lines just battling away and…I just particularly resent being asked for my feedback, or my input and, you know, being included in strategic planning… when nobody really listens to you. (HCP06)

This participant's dissatisfaction reflects the tensions within the system between forces to maintain the status quo and forces of change (Raphael et al., 2008; Tuohy, 2007).

Given the context of rationing, new arthritis programs and services, although rare, were repeatedly positioned by HCP decision-makers as necessarily being “cost-effective,” as demonstrated by research. An example of such a program was the Early RA Program, designed to fast-track people who were in the early stages of RA, so that they could maximally benefit from the newest RA medications. It was deemed cost-effective because research had shown that the newest medications can reduce the need for health services if they are initiated early in the disease trajectory. The endorsement of this program illustrates two shortcomings of “cost-effective” programs. The first is that sanctioning only research-proven interventions aligns arthritis services with the arthritis research agenda. My analysis of fieldnotes, particularly those taken during my participation at an international symposium for arthritis in indigenous populations, suggested that biomedical interventions, RA, and genetics research were prioritized while research into the role of social, material and physical environments (collapsed into the category of “environment”) on the development and experience of arthritis was relatively absent. This was the case despite the fact that many researchers noted the important role of “environment,” particularly as it intersected with gene expression, in arthritis experiences. While the role of the environment was glossed over and constructed as “too expensive and too complicated to research” (Fieldnotes, Sept. 25, 2009), the role of genes was emphasized, reinforcing a view of human health and identity as primarily genetically determined (ten Have, 2001). Hence, the arthritis research agenda continued to prioritize research that is aligned with a biomedical understanding of arthritis. As follows, arthritis healthcare services also prioritized biomedical care, such as the Early RA program.

A second important shortcoming, in the mandate for new services to be cost-effective, is that cost-effective services are more likely to benefit some populations as opposed to others. For example, as noted by this rheumatologist, the Early RA program is unlikely to benefit many First Nations people with arthritis:

> HCP: I'm going to be very honest, we're not seeing early rheumatoid arthritis or early inflammatory arthritis in these First Nations people, and I think part of that is just the fact that, um, they're not being referred. Well, it could be two things, they're not going to the doctors, and they're not being referred. Ah, so I would say, by the time they come here, they're quite flared and well on their way…I can think of a little First Nations lady…probably about 87…she came here, put her in the outpatient day program within the last six months, she has had RA for, I don't know how many years, she has never seen an arthritis specialist in all this time…She lives in [major metro area]. (HCP11)

As this HCP noted, a complex interplay of factors made it difficult for many First Nations individuals to be seen early in their disease. As a result, this new cost-effective program benefited them less than other patients who experienced fewer barriers to accessing care. Cost-effective arthritis research had the potential to benefit people who were already privileged within the system rather than those who were not.

Within the arthritis healthcare setting, discourses of rationing set the stage for prioritization of services. What was prioritized was what had been prioritized in the past: biomedical services. New cost-effective services were similarly shaped by biomedical discourses prevalent in the research arena. As such, arthritis services remained heavily focused on technomedical interventions and specialist services; within this context of fiscal constraints, biomedical discourses tended to be heightened (Baum et al. 2009; Murray, 2009; van Ryn & Fu, 2003).

Attempts to Address Arthritis Healthcare Needs in First Nations Populations

Perhaps in response to the limitations of current services in meeting the needs of First Nations peoples with arthritis, the arthritis centre, which was the primary site of arthritis services fieldwork, embarked on some initiatives to specifically address arthritis in First Nations populations. Two initiatives that were underway were: 1) an initiative to bring new cost-effective services to particular First Nations communities that had specifically asked for services, and 2) an initiative to improve the arthritis specialty support that was provided to nurses working in First Nations communities. Although efforts to create these new services were well-intentioned, discourses of rationing and structural constraints limited the effectiveness of these initiatives.

In the initiative to bring arthritis-specific services to a group of First Nations communities, the desire was to develop an innovative cost-effective model of service that could be replicated in other communities (Fieldnotes, Jan. 10, 2008). Arthritis centre clinicians and researchers met with community members and leaders to discuss the initiative. Despite the good intentions of the arthritis centre staff, the discussion revealed a fundamental difference between what the centre was envisioning and the needs related to arthritis as perceived by the community:

> HCP: We thought that we'd start from the broad, so "What are people's issues?" and then look, based on those issues, "How could Telehealth address the question? How could Telehealth address some of those issues?" not recognizing that when you ask people what their issues are… it sets expectations that you may… that they're hoping that you'll meet those even if it doesn't fit with what a Telehealth intervention can do. (HCP09)

The centre's interest in a Telehealth solution was consistent with biomedical discourses in which technological solutions increased the reach of biomedicine. As noted by arthritis program planners, Telehealth was conceived to be cost-effective because it could reduce the need for specialists to travel to remote and rural locations, thus saving substantial costs associated with travel. As such, it was positioned to address the arthritis problem because it could facilitate specialist intervention, consistent with the assumption that more specialists would result in a reduced burden of arthritis on communities.

In contrast, as noted in the narrative of the HCP who discussed this initiative with me on a number of occasions, the community's priorities for arthritis services were not those that could necessarily be addressed by specialist intervention. Instead, they were intimately related to the context of life in the community:

> HCP: So some of the issues that the community members, whether that was the local docs or the local nurses or the… or folks with arthritis, umm, accessibility was a big one. So getting to services was difficult – people either don't have vehicles…the second issue was pain management. Actually, that was probably the biggest issue…some of the folks with arthritis told us was, umm, their concerns about seeing family, friends being treated just with Tylenol 3, umm, seeing how those are being abused. Umm, they told us about how some people sell the, their prescriptions, once they get them, to other folks in the community. Umm, and [pause 4 sec] just, you know, saying that there has to be a better way to manage pain than Tylenol 3s…Umm, some other issues that came up were the difficulties [following the advice of specialist] …you might be starting an exercise program, you might be doing things to manage fatigue, you might be doing some things to manage pain. So they said that, you know, in the winter, we, we can't go walking because it's too cold and you can't stop and take a break, because [it's too cold to sit] ...they told us about, again, friends and family…that didn't have accessible homes and the people either had wheelchairs or walkers or canes and had difficulty getting out of the home, and when they did get out ambulating, because they had lived in a home that had a gravel driveway and at was probably quite rough and the road was gravel as well and so… we thought, "Hmm. We never thought of it that way." (HCP09)

The results of this community consultation revealed the fundamental chasm between the arthritis expertise developed by arthritis services and the experiences of living with arthritis in communities where there was poor community infrastructure (gravel roads, poor housing, lack of indoor recreation facilities) and poverty (lack of vehicles, selling of prescriptions). Unfortunately, the chasm had been unanticipated by arthritis centre professionals and thus the outcome of the consultation, according to the HCP, was disappointment for all parties. Nonetheless, the arthritis centre forged ahead with the Telehealth initiative, which enhanced the biomedical care that could be provided. Left unanswered was how to address the needs raised by the community, related to the burden of arthritis.

A second initiative that the arthritis services centre had undertaken to improve services for First Nations populations revolved around enhancing the arthritis support for nurses working in First Nations communities. As a first step, nurses were brought to the tertiary care arthritis centre for consultation and education. I participated in this meeting as part of my immersion. The nurses' reports largely mirrored the perspectives derived from the community consultation described above. At this and other consultation activities undertaken by arthritis services, in particular nurses discussed challenges with pain management: "…pain management is coming up over and over again…" (HCP09). Despite this consistent opinion, my discussions with one decision-maker revealed that the first response of the arthritis centre would be to implement the quick and easy solutions ("cull the low hanging fruit"), such as improving communication between community nurses and arthritis specialists of all disciplines. While these approaches may have been laudable in that they provided solutions that were relatively inexpensive, they left unaddressed the complicated expressions of disease and suffering as I have described in this work.

In contrast, there were few suggestions to address the challenge of pain management in discussions. Indeed, many HCPs reported feeling less than adequate in their ability to manage pain. Several HCPs noted that pain management was not a strength of arthritis services. An example is the words of this rheumatologist:

> HCP: I don't think any of us deal that well. I think there's a real lack of dealing with chronic pain, across the board. I mean you've got a few people that are specialized in it, very few, I can think of maybe two physicians that I've come across in B.C., even in [major metro area], that even specialize in it. So we're not, it's just not being addressed. (HCP07)

Without pain management expertise within arthritis experts, it was unlikely that a pain management program would be prioritized in the plan to support nurses in First Nations communities. The lack of pain management expertise among arthritis experts reflected both the arthritis research and service priorities. Pain, because of its complexities, had few identified treatments that could be classified as cost-effective. It was repeatedly positioned by HCPs as an unfortunate byproduct of the disease of arthritis rather than an essential and driving component of the arthritis experience. Pain management was not well addressed in the arthritis care setting.

Community health nurses also reported frustration with the lack of success of self-management programs in their communities. While some reported that they had tried to run such programs, they reported that participation by community members had been poor. I had many discussions with one decision-maker about this conundrum. We revisited this topic during an interview:

> HCP: And so, you know, one of the things you and I talked about was this whole thing about the concept itself and does the concept of self-management fit with First Nations people? And so the first clue I had that maybe it doesn't was…when we asked people to talk to us about all these different arthritis self-management behaviours like exercise and eating healthy to manage weight and, umm, managing stress and managing pain…So we asked people, "What were the pros or benefits of doing these activities and what were the barriers or downsides or consequences of doing these, these activities?" And so we only just by chance happened to have I think it was two First Nations people, and their answers were just so different than everybody else's answers. When they talked about the benefits, they weren't saying the benefits in relation to themselves, they were saying the benefits in relation to other people. So the fellow who said his motivation for exercising was it gave him a chance to do an activity with his family. So he didn't just go and exercise by himself, he made sure that his family all did it together. And then there was another fellow that said that his motivation for eating healthy was not because he wanted to lose weight or because it was good for his health but he said because he wanted to set a good example to the other people in the community… You know, I'd always heard that the family is, is such an important thing for the First Nations and community was so big, and so kind of here was some answers that [supported this]. (HCP09)

As this HCP noted, the lack of success of self-management programs in some First Nations communities may be related to its individualistic orientation (Raphael et al., 2008) that failed to situate the individual within the context of family and community, or it may be related to other factors, such as a high need for support in managing arthritis (e.g. see Gately et al., 2007). Despite its lack of success in First Nations communities, during my immersion self-management programs were repeatedly foregrounded by HCPs as an important tool for managing arthritis in these communities. While some HCPs were concerned about the effectiveness of self-management programs in First Nations communities, proposed solutions were focused on making self-management programs more culturally appropriate rather than questioning the ability of self-management programs (as opposed to programs that offer different kinds of support) to meet the needs of First Nations people with arthritis.

A definite disconnect was evident in the kinds of programs and services proposed and/or available for First Nations communities and the feedback arthritis services HCPs received about arthritis-related community needs. This feedback was aligned with the experiences of arthritis of community members interviewed for this study. The disconnect existed because arthritis services were developed over time in response to biomedical and other discourses; in contrast community needs reflected the complex social context of many First Nations communities. HCP decision makers and program planners had some insight into this disconnect. Their genuine desire to enhance arthritis services for Aboriginal peoples suggests that with more insight, such services can be made more congruent with Aboriginal peoples' experiences of arthritis.

Summary

In the narratives of professionals and my analysis of fieldnotes from immersion in the arthritis services sector there was a strong and consistent acknowledgement by HCPs that healthcare for First Nations patients with arthritis was not optimal. Although HCP narratives underscored the high degree to which HCPs were committed to providing good services to this population, dominant healthcare discourses constrained optimal care. For instance, self-management discourses intersected with culturalist discourses and as a result HCPs tended to view Aboriginal patients, who may have been reluctant to engage with HCP for a number of reasons, as being passive related to a cultural norm. Because of this view, HCPs tended to be frustrated that some First Nations patients did not direct their care. In addition, since the arthritis services were set up in such a way as to require patients to direct their care, First Nations patients who were not demanding were not exposed to some care options.

Although the delivery of optimal care to First Nations patients with arthritis was constrained by the ways in which arthritis services were delivered, stronger constraints were imposed by the structures of arthritis services. Rationing discourses intersected with biomedical discourses to sharpen the arthritis hierarchy that prioritized services for people with RA and left gaps in services for people with complex OA and FM. New services had to be deemed cost-effective to be implemented, linking clinical services with a research agenda that remained entrenched in a reductionist world view. As such, current arthritis services were not aligned with the experiences of arthritis of community members interviewed for this study. Even arthritis services that were specifically targeted for First Nations communities were not aligned with the problems in arthritis management identified by people who work and live in those communities. This reflects an arthritis health services sector that has focused much more on biomedical and technological advances than on addressing the social determinants of health. While this is the norm in health services (Baum et al., 2009; Raphael et al., 2008), data from this research field shows that there is good potential to integrate critical social knowledge into arthritis services settings.

CHAPTER EIGHT: OVERVIEW, IMPLICATIONS, RECOMMENDATIONS, AND CONCLUDING THOUGHTS

This dissertation explored the experiences of health and healthcare reported by members of an urban First Nations community who had arthritis and the ways in which arthritis healthcare services were aligned (or not aligned) with these experiences. In this chapter I provide an overview of the study, discuss the major empirical findings and then the implications and recommendations that follow from the findings. I close with some final thoughts regarding the health inequity of arthritis in Aboriginal peoples.

Overview of the Study and Summary of the Findings

Relevance of the Study

The burden of arthritis in Canadians who identify as Aboriginal is high. With prevalence rates of at least 25% typically reported (e.g. FNC, 2005), arthritis is usually the most common chronic illness in Aboriginal populations. The burden of arthritis is particularly related to the hallmark attribute of arthritis, chronic pain (Edwards et al., 2006), which is notorious for its complexity (e.g. Craig, 2009), poor management (e.g. Phillips et al., 2008), and impact on quality of life and national economies (e.g. Witter & Dionne, 2004). Despite its high burden, arthritis is relatively unstudied in all populations (Ferucci, 2008).

A small, but burgeoning, body of research on arthritis in Aboriginal populations has focused on the genetic underpinnings of rheumatoid arthritis (e.g. Oen et al., 2005), although it is broadly acknowledged that genetic understandings of illness processes will always be partial and incomplete (Lock et al., 2007). There is a dearth of literature that explores the experiences of living with arthritis and social and/or political/historical factors that contribute to the incidence and prevalence of arthritis. In contrast, there is a large body of literature that links the overall health of Aboriginal peoples to: 1) the current poor social and material conditions experienced by many Aboriginal Canadians, related to the colonial history of Canada, and 2) the many barriers to timely, appropriate, and adequate healthcare (Adelson, 2005). This dissertation begins to address the gap in arthritis research by exploring experiences of arthritis and healthcare as described by First Nations community members, and the organization and delivery of arthritis health services.

Methodology, Design, and Methods

This study used a community-based, participatory design that was grounded in decolonizing methodologies, informed by the theoretical perspectives of post-colonial feminism (PCF) and Aboriginal epistemology (AE). The lens of AE was informed and implemented through engagement with a Community Advisory Committee, comprised mostly of elders, and community research assistants. The concept of *Two-eyed seeing*, the merging of traditional Aboriginal ideas with Western epistemologies (Canadian Aboriginal Science and Technology Society, 2005), was used as a guiding metaphor to bring these two perspectives together. Consistent with decolonizing methodologies, the ultimate goal of the research was to privilege indigenous perspectives in the creation of knowledge that can be used towards healing, mobilization, and social justice (Tuhiwai Smith, 1999).

This study had two research fields that relate to the research questions; one was an urban First Nations community and the other was arthritis health services settings. In the first field, I completed hundreds of hours of immersion in the community, over a three-year period, and 24 community members were interviewed with the help of three community-based research assistants. The research assistants were instrumental in interpreting the community-based data through weekly dialogue sessions that were held over 12 months. In the arthritis services field, I completed approximately 100 hours of immersion and conducted indepth interviews with 30 healthcare professionals who provided arthritis services for the region that included the First Nations community. Data from these two fields were brought together for analytical purposes to construct the understandings presented here.

Overview of Major Findings

Situating arthritis experiences within a social and historical context. The analysis of community-based data revealed that experiences of ongoing pain/arthritis and social suffering were inextricably linked to and underpinned by the social and historical context of life in the small urban reserve community. Most participants had multiple sites of bone and joint pain and participants tended to link their pain experiences with specific stories that were related to living with poverty, poor community infrastructure, injuries, violence, and experiences of marginalization. Participants' stories about their painful bodies revealed the hardships of their life and the social and structural issues that shaped their experiences. These findings are consistent with a large body of literature that underscores the role of social factors in shaping health (i.e. the social determinants of health), and a growing body of literature that specifically links colonial legacies with Aboriginal peoples' health (e.g. see Garman & Doull, 2009).

In many stories shared by participants, injuries were featured as a key explanatory factor in the development of arthritis/chronic pain, a perspective common in arthritis literature (e.g. see Roos, 2005). Participants reported having experienced a multitude of injuries over the course of their lives, consistent with the high rates of injuries experienced by Aboriginal Canadians generally (Auer & Andersson, 2001; Berthelot, Wilkings, & Allard, 2004; FNC, 2005; Karmali et al., 2005). According to the First Nations Centre (2005), rates of injuries in First Nations communities are triple the Canadian average. Stories about injuries revealed intersecting contextual factors that contributed to both the injury and ongoing experiences of pain. For instance, some participants suffered trips and falls that led to injuries because of inadequate housing, a feature of life in many First Nations reserve communities (Adelson, 2005; AFN, 2005b). For instance, the Regional Health Survey of peoples living in First Nations communities found that 1/3 of houses were in need of major repairs and another 1/3 were in need of minor repairs (FNC, 2005). This lack of housing adequacy is a by-product of Department of Aboriginal Affairs and Northern Development housing policies that under-resource housing in communities and limit First Nations self-governance around housing (AFN). Thus, high rates of injuries are linked to a colonial history that shapes current social circumstances in First Nations communities. Injuries were discussed by participants as both contributing to the onset of arthritis and also to a worsening of their condition.

There is another line of analysis to consider in understanding the role of social circumstances and social suffering in participants' experiences of arthritis/pain. Emotional trauma and distress were commonly embedded in stories about participants' pain/arthritis. For example, instances of physical abuse that led to injury and ongoing pain were accompanied by descriptions of emotional trauma. Some participants acknowledged that past traumas were remembered (and potentially relived) as current aches and pains were experienced. This context gives rise to a backdrop of emotional distress that is reflected in the high rates of, depression, suicide, and other mental health problems that are found in some, but not all, Aboriginal communities (Brave Heart, 2003; Haskell & Randall, 2009; Kirmayer et al., 2003). In this study emotional distress provided the backdrop against which pain/arthritis was experienced. Since pain and distress are mutually reinforcing (Rashiq & Dick, 2009), the existence of distress played an important role in shaping participants' pain. These findings are aligned with an emerging body of literature that links histories of significant emotional trauma with persistent pain syndromes (e.g. Roy-Byrne et al., 2004; Wuest et al., 2008).

While every participant shared stories of considerable and widespread ongoing pain and disability that reflected a lifetime of hardships, many of which featured significant emotional distress, most also shared stories that highlighted resistance and resilience in the face of these hardships. Participants' stories of hardships were balanced by descriptions of their personal agency and strength. In many instances, stories of suffering revealed participants' abilities to persist or even triumph in the face of adversity, hardships, and ongoing pain, and humour played a role in participants' abilities to be resilient (Hanson & Hampton, 2000; Hayden Taylor, 2005). Participants' stories therefore underscored the complexities of pain experiences and the need to attend to colonial legacies, social suffering, and modes of resistance and resilience when considering arthritis/pain in First Nations peoples.

Living with arthritis: Experiences within the community and with health services. Despite the widespread accounts of significant pain and social suffering, most participants approached their pain with determined acquiescence; although participants often seemed resigned to live with considerable pain, they also often refused to let their pain inhibit their lives. This approach to pain was reinforced by what I interpreted to be a community norm, to suffer in silence. The Community Advisory Committee and the research assistants validated this as a common, taken-for-granted, community expectation. This norm shaped the ways that help for pain was sought.

A finding of this research was that most, but not all, participants were reluctant users of health services, although most had considerable exposure to the system over time. A multitude of factors contributed to this pattern where most participants used the health system as a last resort.

One important factor was prior alienating healthcare experiences. Several participants reported a feeling that their primary healthcare provider (usually a doctor) did not care about them: “He doesn’t like Natives….he never helps me” (P07). Rushed appointments and dismissed complaints contributed to this feeling. For some participants, providers’ derogatory comments, or their persistent focus on the participant’s weight/obesity, were evidence that the provider did not value them as a person. While a few participants searched for new doctors because of these experiences, most did not, preferring to stay with what was predictable rather than having to retell their life/health stories and risk negative consequences. Indeed, consistent with other research (e.g. Browne, 2005; Browne et al., 2011; McCall et al., 2009; Tang & Browne, 2008) every participant shared stories of perceived racism and discrimination that they had experienced during past healthcare encounters. These past negative experiences were readily recalled by participants and were the potential harm against which potential benefits of seeking healthcare were weighed.

In this study, many participants were particularly reluctant to seek healthcare for their pain/arthritis. Many participants relayed that they had received little help for their pain from the health system in the past. Other researchers have found that once Aboriginal individuals with arthritis have failed to receive help for their pain complaints, further pain discussions between them and their healthcare providers are inhibited (Kramer et al., 2002). Further, participants reported that medications were the primary treatment that their physician usually recommended for their pain, and yet many participants reported an aversion to taking medications, especially narcotics, which are a primary tool in the treatment of moderate to severe pain (Jovey et al., 2003). Most participants linked a preference to avoid narcotics with their fears of addiction. In some cases, the fear was related to past struggles with addiction. In other cases, the fear may have been internalized from comments made by health professionals suggesting participants were at high risk of becoming addicted to narcotics (van Ryn & Fu, 2003). The fear of abuse of narcotics is widespread in both health professional and lay populations, so much so that the term *opioid phobia* has been coined (e.g. Weidner, 2010), despite the relatively rare occurrence of addiction (less than 1% according to a recent Cochrane Review; Nobel et al., 2010). This fear intersects with assumptions about Aboriginal peoples' high potential for addiction and abuse of narcotics (including diversion), related to stereotypes that are commonly-held among healthcare providers (Browne et al., 2011; Burgess et al., 2008). As a result Aboriginal peoples are vulnerable to inadequate pain control (Browne et al.; Wuest et al, 2008). The lack of a perceived benefit from accessing health services shaped participants' reluctance to utilize health services.

For many participants, a reluctance to access health services was consistent with a pattern of subjugating their physical needs, where physical needs and well-being seemed to be neglected and ignored. However, while such patterns have sometimes been interpreted as being *self-destructive* (e.g. Alfred, 2009; Brave Heart, 2003; Duran & Duran, 1995; Frohlich et al., 2006; Martin Hill, 2009) and are commonly attributed to internalized feelings of worthlessness and/or severed attachments with land, culture, ways of life, and self and others (e.g. Haskell & Randall, 2009), in this study such patterns seemed to be stemming from resistance towards the health system. Some participants clearly linked a neglect of their physical needs with a desire to avoid healthcare encounters. For example, some participants reported comprehensive routines for the care of their bodies, such as daily stretching and walking. However, when caring for their bodies required accessing healthcare (e.g. for a wrist or ankle injury), they tended to ignore their body's needs. This analysis suggests that a subjugation of the physical, and the associated avoidance of healthcare, can be interpreted as sometimes being linked with resistance towards health services that prioritize physical health.

A subjugation of the physical and reluctance to seek healthcare was reinforced by a community norm, described by participants, to *suffer in silence*. In their stories, nearly every participant made reference to both the pervasiveness of suffering and a belief that suffering was meant to be endured with relative silence. Silence was often positioned in stories as an appropriate response to adversity; it was learned in residential and public schools and also taught intergenerationally in the community. For many participants, family, friends, and health professionals were unaware of the extent of pain that participants endured. Such silencing of Aboriginal voices has clear implications for help-seeking; if people are not comfortable to share their stories of pain and suffering with healthcare professionals, there is little reason to access the health system for chronic pain. In turn, the lack of disclosure of pain and suffering may be a factor in the poor rates of referral to arthritis specialists seen among Aboriginal populations in Canada (Barnabe et al., 2008). Although participants in this study did access the health system when no other options were apparent, they were much less likely to access it for issues of chronic pain and suffering than they were for issues of acute illnesses.

A lack of alignment: The organization and delivery of arthritis health services and the experiences of First Nations peoples with arthritis. The organization and delivery of arthritis health services, shaped by discourses of healthcare rationing, biomedicine, self-management, and culturalism, constrained the extent to which arthritis services could be aligned with First Nations community members' experiences of arthritis. These discourses influenced both the structure of arthritis services and the way in which arthritis health professionals thought about and provided care to First Nations patients they encountered in their practice. Although currently the alignment is poor, the openness of arthritis healthcare professionals and decision-makers to knowledge translation activities suggests that there is good potential to improve this situation.

Despite the fact that healthcare professionals who participated discussed arthritis care for First Nations peoples in ways that demonstrated compassion and concern, the delivery of optimal care was constrained by a variety of factors. For instance, HCPs, who were under considerable time pressures to “get patients through” appointments in an allotted amount of time, described their need to stay focused almost exclusively on biomedical concerns in order to manage their workload. Such an approach suggests that dominant biomedical discourses (e.g. Raphael et al., 2008), are intensified as they intersect with rationing discourses (Baum et al., 2009). Some HCPs noted that the lack of attention to social issues often resulted in the readmission of First Nations patients for exacerbated arthritis. These findings are aligned with a body of literature that calls for more concerted attention to social circumstances as a key component of better health outcomes (Baum et al.; Raphael et al.; Tsasis & Bains, 2008).

HCPs’ work with First Nations patients was shaped by self-management and culturalist discourses. For instance, most HCPs reported that they perceived most First Nations patients to be passive and reluctant to engage with HCPs. This reluctance was often interpreted as an unwillingness/inability to “take responsibility” for health, reflecting the dominance of self-management discourses in chronic illness healthcare settings (Redman, 2009), which suggest that patients should be in control of their illness and direct their care (Redman, 2007). The analysis presented here echoes critiques of the self-management movement found in the literature that question the moral imperative behind the system-wide focus on self-management, which focuses on individual responsibility for health without attention to the social determinants of health (e.g. Gately et al., 2007; Redman, 2007, 2009). Further, passive behaviour was often interpreted by

HCPs as being a cultural trait, revealing the influence of culturalist perspectives, which suggest that culture is a key defining variable that shapes patients’ behaviours (Browne, Varcoe et al., 2009). Although HCPs worked hard to bridge the perceived “cultural barrier” with good communication, the interpretation of reluctance to engage as a cultural trait (underpinned by a narrow understanding of culture) limited an understanding of this behaviour as potentially stemming from historically-rooted power dynamics operating in healthcare encounters (Browne, 2005, 2007). Alternately, one HCP demonstrated a critical understanding of culture after attending related ongoing education, suggesting that critical cultural knowledge can be integrated into HCP practice through knowledge translation (Browne, Varcoe et al.).

The problematic policies and procedures for securing medications and supplies from Non-Insured Health Benefits (NIHB) also constrained optimal care for First Nations patients who qualified for these benefits. Some health professionals lamented about their inability to secure supplies, which had previously been covered, for clients. For example, although foot orthotics remained a covered benefit, the corresponding shoes that allowed orthotics to assist in limiting pain and disability were no longer covered. Given the widespread effects of poverty in many First Nations communities (Adelson, 2005), HCPs acknowledged that some patients would be unable to afford appropriate shoes, rendering the orthotics ineffective. However, HCP had few options to correct this problem, which has been repeatedly noted by Aboriginal organizations. For instance, the Assembly of First Nations’ (AFN) report (2005a) on NIHB acknowledges that the delisting of basic items is short-sighted and contributes to the reality of health inequities in Canada. Similarly, healthcare participants’ reports of the arduous processes for seeking approval for benefits were echoed in the AFN report where procedures for accessing benefits were described as ineffective and onerous. Healthcare participants described their frustrations as requests for coverage were denied without feedback that could direct an appeal; even in cases where coverage was eventually secured, First Nations patients often went without prescribed medications and/or supplies for extended periods. Bureaucratic delays are costly to both patients and providers, and contribute to ineffective healthcare (AFN; Lemchuck-Favel, 1999, 2006). Although NIHB purports to provide a service intended to help "eligible First Nations and Inuit reach an overall health status on par with other Canadians" (Health Canada, 2003b, p. 4), rationing discourses shaped this service in ways that limited its ability to achieve this mandate.

Rationing discourses also shaped the structure of arthritis-specific services in ways that limited the ability of arthritis services to be effective in attending to arthritis in First Nations peoples. For instance, the eligibility criterion for access to most specialized arthritis services was tightened to include only those individuals diagnosed with inflammatory arthritic conditions, primarily RA, as a means to manage wait-lists. While many First Nations community participants interviewed for this study reported multi-joint complex symptoms and life effects that would benefit from the interdisciplinary care that was offered through specialty arthritis services, these symptoms fell under the rubric of osteoarthritis, which was positioned by HCPs as "easy to treat" in primary care and hence not requiring specialized services. The limiting of specialty services to primarily the diagnosis of RA created a gap in services for people with complex OA. Whether or not this gap ought to be filled by arthritis specialty services is not clear; however until this gap is addressed, the poor outcomes of arthritis in Aboriginal populations will probably continue.

Rationing discourses, and the accompanying fiscal constraints, have resulted in a need for decision-makers to make difficult decisions about what services to support. Current services that featured specialist care, and new treatments that were deemed "cost-effective" through research, were prioritized. However, the arthritis research agenda, particularly intervention research, was heavily influenced by reductionist discourses that supported medication and technology related research, and in the case of Aboriginal peoples, genetic-focused research. Research that could have shaped arthritis services towards addressing social determinants of arthritis and arthritis outcomes was relatively absent. Hence, new cost-effective clinical services that have been developed have a limited potential to improve arthritis outcomes in First Nations peoples.

Even arthritis programs designed specifically for First Nations peoples have a limited potential to ameliorate the pain and suffering associated with arthritis in First Nations communities because of a chasm between program expertise and the wants and needs of First Nations communities expressed during arthritis services community consultations. While communities wanted help with issues such as inadequate infrastructure to support the mobility of community members with arthritis, and pain management, the expertise developed in arthritis services was centered on enhancing self-efficacy towards self-management and improving the reach of rheumatologists through technology. This lack of fit left many arthritis-related issues unattended. While the chasm between arthritis expertise and community needs is currently pronounced, the continued engagement of arthritis services program planners and decision-makers with this (and other) research indicates that this chasm might begin to be addressed.

Implications

There are five main implications that arise from these findings. The first two implications are policy implications for federal and provincial services. The third implication relates to arthritis health services and explicates how pain ought to be addressed in this setting. The fourth implication discusses further suggestions for transformations in arthritis health services that would allow services to be better aligned with the experiences of arthritis of First Nations peoples. The last implication is methodological; I discuss what this study tells us about how arthritis research with Aboriginal populations can serve a decolonizing intent. These findings add to the growing discourse on social determinants of health by showing that biomedical approaches to arthritis healthcare ought to be balanced with approaches that address the social context of the patient; the implications discussed here articulate some concrete examples of ways in which a move towards this balance can begin.

Implications for Federal Policy Regarding First Nations Peoples with Arthritis

This study showed how embedded community members' experiences of arthritis were in the context of reserve/community life (Adelson, 2005; Rock, 2003). Arthritis experiences, for community participants, were highly affected by Federal policies applied to people with Status, particularly housing and NIHB policies.

In this study, many community participants lived in homes that posed a significant risk for injury related to a fall; some community participants attributed such falls to their ongoing pain/arthritis and others said that poor housing interfered with their ability to mobilize safely given their mobility restrictions. Housing is an area in need of significant attention. For example, 41% of on-reserve homes are in need of repair in the region in which the study community is located (B.C. PHO, 2009). The inadequacy of housing on reserves seems to be escalating as the "percentage of Aboriginal housing units in need of major renovations increased by 121 per cent" (B.C. PHO, p. 161) between the years of 1994/1995 and 2005/2006. Fortunately, over the past few years there have been several policy initiatives to address this concern. For instance, in 2006 the federal government committed $450 million to address housing and other social determinants of health in Aboriginal populations; in 2007 they announced a $300 million First Nations Market Housing Fund to "broaden the range of housing options for residents of First Nations communities" (B.C. PHO, p. 161). While the dollar amounts of these initiatives seems promising, they are not directly linked with improving the quality of the homes in which people are currently living (i.e. the $450 million is not committed just to housing and the $300 million is to back lenders and enhance credit). Hence, it is not clear that these initiatives will result in safer homes and reduced injuries. What seems to be required is perhaps more in keeping with the memorandum of understanding, to develop a comprehensive approach to housing both on and off reserve, that was signed between the First Nations Leadership Council[35] and the federal government in 2008 (Union of B.C. Indian Chiefs, 2008). This initiative holds more promise because it offers a model of shared governance with First Nations leadership and extensive community consultations (Union of B.C. Indian Chiefs). While the outcomes of this structural intervention have as of yet to be realized, it is interventions like these that hold significant promise to address key factors that contribute to the arthritis health inequities, like inadequate housing.

Similar structural interventions are required to address economic conditions in First Nations communities that impede the ability of community members to live well with arthritis. The current intervention is NIHB. The results of this study show that NIHBs policies may contribute to arthritis inequities because basic requirements for arthritis management (like nutritional supplements, appropriate shoes and appointment with allied health professionals such as physiotherapists) are no longer covered (Lemchuck-Favel, 1999). It is understandable that

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[35] The First Nations Leadership Council is a political body that brings together the political advocacy work of the major First Nations policy groups in B.C., including the Union of B.C. Indian Chiefs, the B.C. Assembly of First Nations and the First Nations Summit. As a cooperative of First Nations political leaders, the FNLC has worked with federal and provincial governments to establish frameworks and agreements in a number of key areas (B.C. Assembly of First Nations, n.d.).

NIHB may need to make decisions about what ought not to be covered because there are significant cost drivers that could threaten the economic viability of the program (Lemchuck-Favel, 1999, 2006). For instance, medications currently consume approximately 45% of the total expenditures for NIHB (Health Canada, 2008) and new biologic, disease-modifying agents for arthritis are among the top five drug products by expenditure (AFN, 2005a). An analysis of expenditures for biologics over the years 2004 to 2007 (McDonald, 2008) shows that although these drugs are given to a comparatively small (but growing) group of individuals, their proportion of the budget is increasing. In 2006, $1,617,437.01 was spent on analgesics for 25,431 clients, while $1, 557,709.32 was spent on biologics for 157 clients. I provide these figures to show how a new drug, that benefits a proportionately small number of individuals, can be equally as costly as a drug that benefits approximately 160 times more individuals. I am not suggesting that patients be given an analgesic instead of a disease-modifying drug. However, I am suggesting that with the current focus on pharmaceutical research, there will be many more significant cost drivers emerging (Baum et al., 2009) and difficult decisions about what ought to be covered will need to be made. Research has shown that improving health at the population level is more effective at reducing health inequities than strategies aimed at improving health for specific individuals (Baum et al.; Rock 2003). Hence, funding health supplies that have broader effects on populations is a more effective strategy for addressing health inequities than funding products that focus on the health of a few individuals. Ensuring that a population living with arthritis has adequate access to nutrition, good walking shoes, and comprehensive primary care (i.e. access to physiotherapists) will be more effective at reducing arthritis inequities than providing biologics to a few patients who may not fully benefit from the drug given that the drug will probably not be introduced early in the disease trajectory. These are difficult decisions and demand that a discussion of underlying values is undertaken (Kenny, 2002). If NIHB is to be effective in bringing the health of status First Nations up to par with the rest of Canada (Health Canada, 2003b), a review of priorities for funding is warranted.

Implications for Provincial Policy Regarding Chronic Illness Management

The findings of this study suggest that there are gaps in services available for people experiencing complex chronic illnesses, like many of the community members interviewed for this study. Current provincial health policy in B.C. identifies the Expanded Chronic Care Model as the target for system re-design to better align the health system with the needs of people with chronic illness (see Chapter Two). However, while a few policy initiatives have aimed to enhance physicians' management of chronic diseases through incentives to meet standardized clinical practice guidelines (B.C. Ministry of Health, n.d.), the vast majority of chronic illness initiatives have been directed at enhancing self-management capabilities (e.g. Centre on Aging, n.d.). In contrast, a chronic illness management model developed in the U.K. provides a different way of thinking about needed programs to support people with chronic illness (Gately et al., 2007). It suggests that policy initiatives ought to address three levels of support for patients according to their needs: "*case management* for patients with multiple, complex conditions; *disease management* for patients at some risk, through guideline-based programmes in primary care…; and *self-care support* for low-risk patients" (p. 934; italics in original). While B.C. seems to be addressing the need for self-care fully and the need for disease management to a certain extent, there is a notable gap in policy that would enable case management for people with complex OA/chronic pain. Currently, the management of chronic illnesses reflects an "essential mismatch, within our existing systems, between health-services investment and the social reality of [chronic] illness" (Thorne, 2008, p. 8).

Ethical questions arising from the focus on self-management. There are several important ethical questions to be considered when self-management is positioned as the primary tool for chronic illness management that are reinforced by the findings of this study. One ethical question is "for whom have self-management programs been designed?" As noted in Chapter Two, self-management works well in populations that self-select to participate. Redman (2007) characterizes this as "educated middle class with high reading levels" (p. 244). Conversely, self-management has little likelihood of success in populations with a "troubled emotional state, low self-efficacy, conflicting personal health beliefs, physical limitations, lack of knowledge about their medical conditions, and the presence of co-morbid diseases" (Bayliss, Ellis, & Steiner, 2007, p. 396), characteristics shared by many community participants. Hence, the promotion of self-management as the primary tool for chronic disease management has the potential to contribute to the arthritis health inequity, widening the gap between "the *Haves* and the *Have Nots*" (Redman, 2007, p. 248) by primarily working to enhance the health of people with arthritis who are already relatively privileged within society (Rogers et al., 2008).

A second ethical question related to self-management discourses is "what basic belief about humans does self-management promote?" As discussed in Chapter Two, self-management is aligned with neo-liberal ideologies that position humans as freely choosing individuals bearing primary responsibility for their health (Raphael et al., 2008). However, the findings of this study suggest that while community members showed agency, complex socio-historical factors, most of which were far beyond individual control, constrained the choices available and their arthritis/health experiences. As a result, First Nations patients are at risk of being labeled as "non-compliant" (Asimakopoulou, 2007), or as in this study "passive", because they cannot demonstrate that they are "in control at all times" (Asimakopoulou, p. 94). In casting First

Nations patients as passive, these discourses reinforce images of First Nations people as incapable of mounting an appropriate response to illness. This contrasted with community participants' resistance and resilience as people who were actively managing their pain/arthritis albeit in ways that might not have always been congruent with the expectations of healthcare professionals. Therefore, self-management as the ideal or only option for chronic illness management not only fails to meet the needs of many First Nations individuals with arthritis, it may also be reinforcing negative stereotypes of Aboriginal peoples.

Case management as a policy initiative to improve chronic illness management. Calls for a chronic illness resource that accounts for the material and social conditions of patients and provides support over a long term have been repeatedly made (e.g. Francis, Feyer, & Smith, 2007; Gilmer et al., 2007; May et al., 2009; Mitton, O'Neil, Simpson, Hoppins, & Harcus, 2007; Rogers et al., 2008). Such a resource would no longer position the "crux of the [management] problem as the disease" (Thorne, 2008, p. 10) or the patient (Redman, 2007, 2009). Instead, the focus of care would be on helping patients to live well with their chronic illness, given the complexities of their everyday life, by creating an individualized, ongoing plan for support (Thorne). As noted by May and colleagues (2009), policy initiatives are needed that do not add to the burden of already overburdened patients.

A variety of options for case management are reported in the literature. Some options provide continued support in person (e.g. Mitton et al., 2007), while others provide ongoing support primarily via telephone calls (e.g. Alkema, Wilber, Shannon, & Allen, 2006). Regardless of the mode of delivery, these programs have shown to have impressive outcomes including reduced mortality (Alkema et al.), decreased acute care service utilization (Gilmer et al., 2007; Mitton et al.), and improved quality of life (Gilmer et al.; Mitton et al.). The success of these kinds of initiatives seems to rest on their abilities to enable comprehensive professional assessments of the patient’s life context, individualized versus standardized plans of care, on-going monitoring of successes and challenges, and bridging of medical and social services delivery systems (Alkema et al.). These models have been almost exclusively delivered out of primary care settings and are thus value-added components of the primary health system that are particularly targeted towards people with chronic illnesses, such as those with complex arthritis, who are at high risk for poor outcomes related to the complexities of their life circumstances (Gately et al., 2007). Such a service would be of tremendous benefit to community members interviewed for this study.

Healthcare policy that would see case managers added to primary health services could go a long way in reducing the health inequities in arthritis experienced by Aboriginal peoples in Canada. Unlike the self-management initiative, which is positioned to benefit people in the top end of the socio-economic hierarchy, a case management initiative would benefit people in the lower end of this hierarchy (Gately et al., 2007; Gilmer et al., 2007). Such a service would be well positioned to help patients with complex, socially-embedded arthritis begin to address their health needs through highly individualized approaches that can account for the material and social aspects of their life (Kendall & Rogers, 2007).

Incorporating the Concept of Total Pain into Arthritis Care Services

The concept of total pain, a view of chronic pain as a holistic expression of a multitude of factors, such as social, emotional, psychological and physical (Clark, 1999), although prevalent in some chronic pain arenas, seems to be under-utilized in the arthritis field. A finding of this study was that pain management seemed to be neglected among healthcare participants and in the arthritis services arena. This is despite the fact that pain remains the cardinal symptom of arthritis and is heavily implicated in contributing to disability and poor quality of life (Edwards et al., 2006; Health Canada, 2003a). A formalized adoption of the concept of total pain into arthritis services, and the development of targeted services for the management of total pain, would greatly enhance the service provision to Aboriginal (and non-Aboriginal) populations.

The relevance of the experience of chronic pain to First Nations peoples with arthritis was clearly articulated with this study. In reconceptualizing arthritis, community elders on the Community Advisory Committee chose to foreground "aches and pains." This spoke loudly as to the central concern around arthritis for this community. In addition, healthcare participants who were active in program planning for arthritis services in First Nations communities noted that pain was the most commonly raised issue for arthritis management by First Nations community health nurses. The dynamics of the total pain experience are such that issues of hardship and suffering, which were widespread among community members who participated in this study, and in many First Nations communities (Adelson, 2005), merge with pain generated by bone and joint pathology to produce significant and often disabling pain (Campbell & Edwards, 2009; Craig, 2009; Gagliese & Katz, 2000; Sharp, 2004). Chronic pain concerns are central to the burden of arthritis in all populations (Perruccio et al., 2005).

A program of total pain management in First Nations populations with arthritis would be able to attend to issues of hardship and suffering and thus be consistent with a trauma-informed care approach[36] (Elliot, Bjelajac, Fallot, Markoff, & Reed, 2005). While a total pain approach would be fundamental to the practice of every discipline, this concept seems particularly relevant to nursing practice, irrespective of the domain of practice, given nurses’ commitment to holistic care, role in coordinating interdisciplinary services, and longitudinal and in-depth exposure to many patients. Each patient’s unique life story would be considered to identify factors that are contributing to the total pain experience (Craig, 2009; Gagliese & Katz, 2000). Patients would be helped to identify contributing factors in order to overcome the effects of dominant pain discourses that legitimize physical pain while marginalizing or delegitimizing pain sources that are not physical (Craig; Gagliese & Katz). Careful attention to the well-being of patients will be necessary, particularly in instances where issues of violence/trauma are intertwined with the pain experience (e.g. Wuest et al., 2008), so that people are not re-traumatized through the telling of their stories (Elliot et al.). Further, there is some evidence that understanding pain from a total pain perspective can, in and of itself, contribute to better pain control (e.g. Butler & Moseley, 2003) in addition to fostering plans for pain management are holistic. For many, like community participants in this study, these plans will have to include linkages with other health and social services, for example, mental health practitioners, social workers, and social assistance programs.

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[36] Trauma-informed care is an immerging approach to health services that seeks to identify and treat instances of trauma whose impact on health have been, in most contexts, unacknowledged. While being careful not to re-traumatize an individual through recounting past traumas, trauma-informed care seeks bring to the forefront the ways in which histories of trauma influence current health experiences (Elliot et al., 2005; Wuest et al., 2008).

Currently, few tools are available to guide health professionals in the management of chronic/total pain in Aboriginal populations (Kramer et al., 2002). An appropriate tool would need to be grounded in concepts and language that is locally relevant to Aboriginal individuals and communities (Castellano, 2000). The use of concepts that are well-accepted in Aboriginal communities, and offer the opportunity to reinforce individual’s identification with their community, promote health (Brave Heart, 2003; Kirmayer et al., 2003; Waldram et al., 2006). Arthritis services personnel, because of their extensive experience in providing care to Aboriginal peoples experiencing chronic pain, could partner with communities and community members with chronic pain to develop tools and expertise.

Such tools and expertise should provide guidance in chronic pain management for the benefit of not just the individual First Nations person but for First Nations communities (e.g. Lalonde, 2006). A toolkit could be developed to help communities create comprehensive approaches for pain management. Such toolkits have been developed for issues like nutritional labeling (Health Canada, 2004) and childhood obesity (Best Start Resource Centre, 2010). A chronic pain management toolkit could provide guidance for community leaders and health workers to understand the complexities of arthritis (e.g. in seeing arthritis as not just a biomedical diagnosis), as well as the myriad of factors that contribute to the experience. It could provide guidance on how communities could address some of the structural issues, such as housing and the need for good sleep surfaces, which are contributing to pain and arthritis, as well as develop programs to address some of the issues of social suffering. The provision of concrete guidance could influence the priorities that are made, and the lobbying approach used, by communities to secure specific services. Such a toolkit would need to be developed in partnership with First Nations communities to ensure that it is useful to the communities for which it is intended. Addressing the total pain experience of Aboriginal peoples with arthritis is a critical part of addressing the burden of arthritis in Aboriginal communities.

Transformations in Arthritis Services Organization and Delivery

Healthcare professionals working in the field of arthritis are constrained in their ability to provide services that address the burden of arthritis in Aboriginal populations. While the vast majority of professionals interviewed for this study were committed to providing good care to Aboriginal individuals with arthritis, their ability to influence the experiences of Aboriginal peoples with arthritis was hampered by the organization and delivery of arthritis services. Like most other health services arenas, arthritis services were shaped by a biomedical understanding of arthritis; services that could address the social determinants of arthritis were rare. Three transformations would provide directives for improving services: 1) adopting a model of cultural safety in the delivery of arthritis services, 2) restructuring arthritis services to include services for complex osteoarthritis, and 3) critically questioning the link between research and clinical services.

Drawing on ideas from cultural safety in the delivery of arthritis services. In this study, healthcare professionals appreciated and recognized culture as an important concept. Yet, in the presence of predominant culturalist approaches (like cultural sensitivity), healthcare professionals tended to draw on narrow conceptualizations of culture and engage in racializing practices. While understanding a patient's culture is important, this study showed that historical and social factors were more salient forces in shaping health, experiences of living with arthritis, and participants' utilization of healthcare. The concept of cultural safety has been used in Canadian contexts to disrupt culturalist discourses in healthcare by fostering an approach that encourages professionals to attend to historical, social, and political factors that profoundly influence culture as well as shape both health and healthcare encounters (Browne, Varcoe et al., 2009). Such an approach attunes professionals to the contexts of patients' lives, as well as the power imbalances that are operational in healthcare encounters. Further, research has shown that patients from any background can be racialized and disadvantaged during healthcare encounters; therefore, all patients can potentially benefit from a cultural safety approach (Anderson et al., 2003).

The concept of cultural safety has been applied in varying ways and in varying contexts in Canada. One useful approach to translating the concept of cultural safety into clinical practice was proposed by Browne, Varcoe and colleagues (2009). In this interpretation, cultural safety is not characterized by a set of behaviours or attitudes that healthcare professionals must abide by. Instead, it provides a lens through which healthcare professionals can view their practice, in particular (but not limited to) their encounters with patients viewed as cultural Others. The cultural safety lens fosters awareness of processes of racialization, of inequitable social relations, and of political, economic, and historical forces that shape health, healthcare, and healthcare encounters. This lens would, for example, allow healthcare professionals to critically analyze their assumption that First Nations arthritis patients are passive, and could raise awareness about the impact of past historical events, such as residential schooling, on power relations in healthcare.

Introducing such concepts and content into healthcare practices is difficult, complex and would require a commitment to cultural safety by healthcare leaders (Browne, Varcoe et al., 2009). Changing attitudes and practices that have become entrenched and are sustained through predominant discourses requires engaging healthcare professionals in learning activities, like discussions of evidence related to the social determinants of health, as well as opportunities to critically reflect on practice, over a sustained period of time (Browne, Varcoe et al.). Healthcare professionals will require that some time is sanctioned to participate in these activities. While this approach may be ideal, given the highly time pressured healthcare environment, it may be more feasible to promote independent learning among healthcare professionals. A variety of web-based learning opportunities are available that teach the subject of cultural safety, consistent with the interpretation advocated for here. For example, the University of Victoria offers a no-cost on-line course on cultural safety (Dick et al., 2006). Similarly, Provincial Health Services Authority (PHSA) offers no-cost Indigenous Cultural Competency Training to PHSA health workers (http://www.culturalcompetency.ca/home). While such courses are designed for self-learning, they could also form the basis for a series of in-hospital educational sessions that would capitalize on reflective discussions. While research exploring effective ways to integrate the concepts and content of cultural safety into practice is sparse, the need to integrate cultural safety into practice is great; as such health leaders should begin this integration project and allow their context-specific experiences to shape the integration process. A system-wide integration of cultural safety into care would be optimal; however, in terms of improving healthcare for First Nations peoples with arthritis, arthritis services are an especially important target for this integration because Aboriginal peoples make up a significant proportion of the population served.

Restructuring arthritis services to include services for complex osteoarthritis (OA). Beyond the way arthritis care is delivered, the organization of arthritis services contributes to the gaps in the ability of arthritis services to address the burden of arthritis in Aboriginal populations. The assumptions that current services need to be “protected,” and that new services must be deemed “cost-effective” in order to be implemented, must be challenged. Priorities in service delivery should be reconsidered if arthritis services are to address the burden of arthritis in Aboriginal populations.

The current mandate to protect current arthritis services for people with rheumatoid (and other inflammatory) arthritis, while positioning people with OA as ineligible for most arthritis services, diverts attention from the immense burden that is related to osteoarthritis. In addition to the problems associated with obtaining a diagnosis of inflammatory arthritis in Aboriginal populations (as discussed in Chapter Seven), the current organization of services created a gap in services for the many Aboriginal and non-Aboriginal people who have complex OA. Although there are some services for people with osteoarthritis in British Columbia through the OASIS (OsteoArthritis Services Integration System) program, this service is primarily geared towards the hip and knee replacement surgical population; it provides comprehensive assessment and recommendations for management (mostly self-management) for people with OA of the hip or knee, but it is not set up to offer management/treatment outside of the surgical arena. On the other hand, the arthritis services explored in this dissertation could offer treatment and management for complex arthritis of all forms, as has been the case in the past. Some community participants in this research wanted access to, or could have benefited from, programs such as the therapeutic pool program, hand classes, and especially the outpatient day program offered through arthritis services. What is needed, therefore, is a re-thinking of the eligibility criteria. If eligibility was based on factors such as the number of joints involved, the degree of impairment, and the complexity of management issues, many community participants might have been eligible. In this way, patients would be prioritized according to need rather than according to diagnosis. The current decision to base eligibility on diagnosis is based on an assumption that OA is *simple* to manage; OA has become the proxy for simple arthritis. This study shows that OA is not necessarily simple, and that lines between OA and RA are not always clearly delineated.

Critically questioning the link between arthritis research and arthritis clinical services. The mandate that new arthritis services be identified as cost-effective through research reflects an assumption that clinical programs are best directed by research knowledge, reinforcing the appropriateness of a “one-way transmission of privileged academic knowledge” (White, 2009, p.2) from research to practice. This assumption positions other sources of knowledge as being less relevant for directing clinical services development and, as such, it draws on narrow interpretations of evidence/knowledge in which certain knowledges are sanctioned while others are concealed or discredited (Cheek, 2007). It obscures the fact that the research agenda is shaped by factors that promote some types of research while marginalizing others. For instance, technology and medications are prioritized in intervention research while social, emotional, and psychological interventions receive far less attention (Kirwan et al., 2003). As a result, the vast majority of new services introduced are based on technology, such as Telehealth, and new RA medications. In order to address the burden of arthritis in Aboriginal populations, arthritis services ought to be advocating for a broadened research agenda: one that balances the exploration of medications and technologies with research on other kinds of interventions/programs. In this way, a body of research can be constructed that can direct the development of services that go beyond medicines and Telehealth. In the meantime, arthritis services could draw on other sources of knowledge (White), such as elders or community members, in the development of services that could reduce the burden of arthritis in Aboriginal populations.

Two-eyed Seeing as a Metaphor for Partnership Methodologies in Arthritis Research

This research offers methodological lessons about the possibilities for arthritis research to contribute to not just better arthritis care but also to the project of decolonization. Both the field of Aboriginal peoples' health research and the field of chronic illness research (among many others) underscore the need to learn from the perspectives of the people who are living with illnesses (Rock, 2003; Thorne, 2008). Decolonizing research is aligned with this articulated need, for if researchers are truly learning from the perspectives of Aboriginal peoples, then communities will need to have some power and control in the research process (Bartlett et al., 2007; Battiste, 2008; Tuhiwai Smith, 2005). If the field of arthritis in Aboriginal populations is to learn from the perspectives of Aboriginal peoples who have arthritis, then partnership models, such as those based on Two-eyed seeing, will be required.

The utility of partnership models in contributing to decolonization is incumbent on incorporating indigenous perspectives at the level of theoretical underpinnings of the study. Because all research activities, from conceptualization of the focus of research to the interpretation and translation of the findings, flow from the theoretical perspectives behind the research, incorporating indigenous perspectives as this level enhances the ability of the research to contribute to the larger political struggle of Aboriginal peoples (Fletcher, 2003).

Whenever communities are involved in research in ways that foster indigenous perspectives to be truly present and shape the entire research process, the potential for research to contribute to the project of decolonization is enhanced (e.g. Battiste, 2008). In the field of arthritis research, which has been dominated by biomedical and academic understandings, there is much to be learned by ensuring that the perspectives of those who are living with arthritis in Aboriginal communities are incorporated.

Recommendations Arising from this Study

Based on the outcomes of this study, the following recommendations have been formulated to provide direction in the areas of policy, health services, research, and education. These recommendations have been deliberately made as concise and concrete as possible so that they can be readily accessed and applied.

Policy

1. Federal housing policy for reserve communities should continue to be shaped by memorandums of understanding between Aboriginal leadership organizations and the Federal Government with the aim of eliminating poor housing, which places people at high

risk for falls and inhibits mobility in people who are physically compromised.

2. NIHB should reinstate previously covered benefits that support overall health including nutritional supplements, shoes when orthotics are provided, and access to allied health professionals.
3. NIHB should provide clear and timely communication, including outlining appeal processes, to healthcare professionals whenever applications for coverage are denied.
4. NIHB should reconsider the need to have physicians sign for prescriptions made by allied health professionals. This would allow more timely access to benefits for Status First Nations patients as well as create consistency for healthcare professionals by creating a common requirement for signatures between Federal and Provincial programs.
5. Provincial health services and local health authorities should establish and promote a case management approach for individuals who have complex chronic illness.

Health Services

6. Chronic disease management services should be provided through three strategies for three populations experiencing chronic illness: 1) case management for patients with multiple, complex conditions, 2) medical management for patients who are at some risk for poor outcomes, and 3) self-management support for patients who are at low risk for poor outcomes (Gately et al., 2007; Tsasis & Bains, 2008).
7. Patient advocacy positions should be implemented in the arthritis services setting so that the needs of patients who struggle with meeting the institutional requirements for care (i.e. have trouble negotiating appointments and/or interpreting recommendations) have a knowledgeable other person who is able to act on their behalf.
8. Arthritis services should implement a total pain approach to arthritis care. Such an approach

would ensure that patients' traumatic histories and issues of social suffering are incorporated into assessments and management plans in appropriate ways.

9. Arthritis services should develop a mattress program that would enable people with chronic pain/arthritis to obtain appropriate sleep surfaces. Some mattress retailers are already involved in donating mattresses and could be recruited to participate in such a program (e.g. see Sleep Country, http://www.sleepcountry.ca/charities).

Community Services

10. Injury prevention programs in First Nations communities should provide programming that addresses the factors that contribute to injuries that often manifest as arthritis in later years.
    a. Attention to the safety of housing, in terms of stair banisters, bathroom adaptations, ramps, etc. needs to continue.
    b. Attention to the issues of interpersonal violence and substance use, as contributors to injuries and arthritis, needs to be enhanced in communities.
11. Nurses working in First Nations communities should be providing arthritis care based on a total pain approach. They should continue to be vocal about the need for better chronic pain management resources for use within communities.

Research

12. CIHR (Institutes of Musculoskeletal Health and Arthritis and of Aboriginal Peoples' Health) should formally encourage research that will develop knowledge on the role of environment (e.g. family factors, socio-economic factors, community factors, and historical considerations) in the development and outcomes of arthritis in Aboriginal populations.
13. Arthritis research organizations like the Arthritis Research Centre of Canada (http://www.arthritisresearch.ca/) should articulate a commitment to partnership-based

methodologies in research with Aboriginal peoples.

Education

14. Arthritis services should endorse cultural safety training as a useful direction to prepare staff to work knowledgably and ethically with all patients regardless of their social background.

Concluding Comments: The Lesson of Two-eyed Seeing

When I first engaged with the concept of Two-eyed seeing I was excited about blending two knowledges that are reflective of two world-views, traditional Aboriginal knowledge and contemporary science. I was compelled by the idea of blending these two knowledges that are usually described as being in conflict and I was sure that this double lens would be important for *good* research with Aboriginal peoples. In the end, the use of these two knowledges allowed me to understand the complexities of arthritis in First Nations peoples and arthritis services. However, the lessons garnered from two-eyed vision extend beyond the utility of using these two knowledges to answer important research questions.

Two-eyed seeing teaches a broader lesson about the shortcomings of binary thinking, which dichotomizes and places as incommensurable and polar opposites concepts that are better understood as complementary and indeed interdependent and with fluid and shifting boundaries. As an example, people who are often viewed as being typically passive must also be viewed as having power and agency; First Nations participants were agents in managing their pain. Also, two-eyed vision allowed me to recognize that the health system continues to operate predominantly from a one-eyed position, that of a physical-genetic-biomedical eye. And yet, the responsiveness of arthritis healthcare professionals and leaders to this work suggests that there is good potential to move to two-eyed vision in healthcare. Such an outcome would have biomedical knowledge integrated with knowledge based on critical perspectives and underscoring the social determinants of health. Like Aboriginal and scientific knowleges, biomedical and critical/social knowledges can be knit together for more comprehensive and hence effective healthcare (Anderson et al., 2010). The major lesson of two-eyed seeing is one of integration.

Hence, the lesson of two-eyed seeing is to seek multidimensionality, “the utility and wholeness to be discovered or reaffirmed” (Urion, 1999, p. 10). With respect to this research, community participants were complex, integrated humans; their social suffering was woven together with their bodily injuries (and/or genetic predispositions) in the phenomena typically labeled arthritis. Further, their past was operational in the present. It is with these kinds of multifaceted understandings that people with aches and pains can begin to get their health needs met. Indeed, such approaches reaffirm health as much more than the absence of disease.

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APPENDICES

Appendix A: Letter of Agreement between the First Nations Community and the Student

LETTER OF AGREEMENT

Between [name of Nation], and
The Project Team *

* Project Leader, Heather McDonald (Doctoral Candidate) and Dissertation Committee (Dr. Joan Anderson, Dr. Annette Browne, Dr. Michael Marker, Dr. Rod McCormick, Dr. Carol Jillings)

Re: The organization and utilization of arthritis health services for First Nations peoples living in B.C.

This research project is part of the requirements for a doctoral degree in nursing (Heather McDonald) and is funded in part by the student's doctoral awards (CIHR and MSFHR) and a grant from the School of Nursing, University of British Columbia.

The research will occur within the context of a full partnership between the Project Team and [name of Nation]. *A community-based Advisory Committee*, with [name of Nation] elders as core members, has been struck. The Advisory Committee, in collaboration with the Project Team, will provide oversight and guidance for the research.

The purpose of this letter of agreement is to outline the responsibilities of the Project Team, and in particular the Project Leader (Heather McDonald), in ensuring that the research unfolds in a way demonstrates a grateful spirit towards the Nation for facilitating the research. The research will be conducted with full adherence to the following principles **

RESPECT is demonstrated toward Aboriginal Peoples' cultures and communities by valuing their diverse knowledge of health matters and toward health science knowledge that contributes to Aboriginal community health and wellness.

RELEVANCE to culture and community is critical for the success of Aboriginal health training and research.

RECIPROCITY is accomplished through a two-way process of learning and research exchange. Both community and university benefit from effective training and research relationships.

RESPONSIBILITY is empowerment and is fostered through active and rigorous engagement and participation.

** Taken from the B.C. ACADRE website http://www.health-disciplines.ubc.ca/iah/acadre/site_files/research/4_r_s.htm. Retrieved October 18, 2006.

The four R's are based on Kirkness, V. J. and R. Barnhardt (2001). First Nations and Higher Education: The Four R's - Respect, Relevance, Reciprocity, Responsibility. Knowledge Across Cultures: A Contribution to Dialogue Among

Civilizations. R. Hayoe and J. Pan. Hong Kong, Comparative Education Research Centre, The University of Hong Kong. http://www.ankn.uaf.edu/IEW/WINHEC/FourRs2ndEd.html

The Project Team acknowledges the principle of *community ownership of data.* As such, each and every participant from [name of Nation] will be asked if they would like their data returned to them. The data could include the original tape recording of an interview and/or the written transcription of the tape recording (with identifying content removed), depending on the wishes of the participant. A copy of all transcripts and tapes will be held by the Project Leader, in accordance with the requirements of the University of British Columbia (UBC). In accordance with the current UBC ethical guidelines, these data will be held for a period of five years after completion of the study and then destroyed (paper will be shredded and discs/tapes will be destroyed).

The Project Team acknowledges the need for *findings from the research to be used in a way that is beneficial to the community*. As such, any reports or publications stemming from the research will uphold this responsibility, demonstrate respect for [name of Nation], and honor the participation of [name of Nation] community members.

Signatures indicating an agreement with this Memo of Understanding

______________________________ ______________________________

Designator signatory from [name of Nation] Date

______________________________ ______________________________

Designator signatory from Project Team Date

Breakdown of responsibilities and commitments

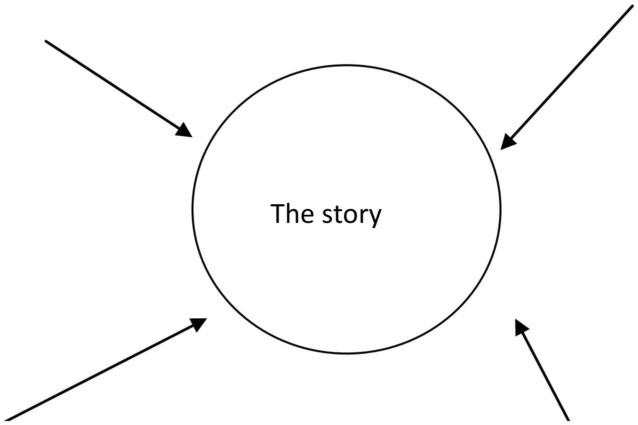
1. Project oversight
    a. The [name of Nation] agrees to delegate responsibility for this project to the elder’s group via an Advisory Committee.
    b. The [name of Nation] agrees to allow participation in the Advisory Committee by the elder’s coordinator and other interested and relevant community members, for example the CHR and Council members, as part of their [name of Nation] work.
    c. The meals and transportation for meetings will be covered by the student’s doctoral awards.
2. Research Assistant
    a. The [name of Nation] agrees to facilitate the recruitment of a community member for the position of research assistant (RA) to the project through advisement of advertising venues.
    b. The Project team agrees to provide training in research and research methods to the research assistant.
    c. The research assistant will be remunerated from the student’s doctoral awards.
    d. The Project team agrees to provide a letter to the RA, outlining training and skill development, at the conclusion of the study.
3. Research participants
    a. The [name of Nation] agrees to facilitate recruitment of participants through access to the elders’ group and community newsletters, and by allowing the posting of flyers in communal areas.
    b. The Project team agrees to provide multiple opportunities for recruitment
        i. Researchers will present the research to elders and other community groups
            1. Notice of the presentation will be made in community newsletters
            2. Flyers advertising meetings will be posted in communal areas
        ii. Pamphlets, describing the research project and participant commitments, will be available for community members to take home while they decide about participation.
4. Dissemination of findings
    a. The [name of Nation] agrees to facilitate sharing/dissemination of research findings as recommended by the Advisory Committee.
    b. The Project team agrees to ensure that findings are shared/disseminated as per the recommendations of the Advisory Committee.

Appendix B: Interview Guide

Key interview topic areas: [name of Nation] Arthritis and the healthcare system study, 2007/2008.

Provide context. Social chit chat. Confidentiality. Consent.

1. Tell me about your aches and pains.



1. How long have you had them? Have they been diagnosed?
2. Signs and symptoms
3. Thinking about daily life (family, friends, work), what changes in life have resulted?
4. What's up ahead for you and your arthritis?

Explain might need time to think. Remind can skip questions.

5. Do you have any ideas about what caused your aches and pains or why they started when they did?
6. What kinds of things do you do to manage your aches and pains?
    a. Medications taken
    b. Physical activities/daily routines
    c. Dealing with the emotions
    d. Traditional practices?
    e. Obstacles. What is stopping you from….
    f. Who helps? Who else could/should help?

Brief about scope of healthcare system: from community services to federal.

7. Tell me about your experiences with the healthcare system.
    g. Good and bad
    h. What are the reasons for these experiences?
    i. What are your recommendations for the community, for BC health services and for the federal government?

Check in (other comments). Remind about follow-up. Give

Appendix C: Consent Forms

THE UNIVERSITY OF BRITISH COLUMBIA

School of Nursing
T201- 2211 Wesbrook Mall
Vancouver, BC Canada V6T2B5
Tel: (604) 822-7417
Fax: (604) 822-7466

The Organization and Utilization of Arthritis Health Services for First Nations Peoples in the Southern Mainland Area of B.C.

Letter of Consent for Participant Observation and Interview (First Nations Participants)

Doctoral Candidate
Heather McDonald, RN, MSc, CRRN
UBC School of Nursing

Dissertation Committee Supervisor
Annette Browne, RN, PhD
Associate Professor
UBC School of Nursing

Co-Supervisor
Joan Anderson, RN, PhD
Professor Emeritus
UBC School of Nursing

Committee Members

Michael Marker, PhD
Associate Professor
Educational Studies, UBC

Rod McCormick, PhD
Associate Professor
Educational and Counselling Psychology, and Special Education, UBC

Dr. Carol Jillings, RN, PhD
Associate Professor
UBC School of Nursing

You have been invited to participate in this study because you have arthritis and you live in the community that is a part of this study. This study is being conducted as part of the doctoral degree in nursing for Heather McDonald.

Background

Arthritis is a very common chronic condition affecting about one out of every six people in Canada. It is even more common in Aboriginal peoples, affecting nearly one out of every four people. We know that getting health services is complicated for First Nations peoples because of the many levels of government involved. We also know that the system could work better for everyone with a chronic illness. We don't know, however, how well the health system is meeting the needs of First Nations peoples with arthritis. We want to understand what works and what could work better, when it comes to arthritis services for First Nations peoples, so that we can suggest improvements. During this study, both First Nations arthritis sufferers and healthcare professionals will be invited to help examine the health system.

Participation and Reporting

In order to learn more about your needs for, and use of, healthcare, Heather (or a research assistant from your community) will either interview you, or spend time with you (observations) as you care for your arthritis, or both. Interviews will occur when and where you wish and may occur several times over the course of the study (6 to 8 months). They will take between 20 and 60 minutes. Interviews will be tape-recorded, if you agree. At any time you can decline to be interviewed or end/stop an interview.

For the observations, Heather (or the research assistant) will spend time with you, for *up to* two hours at a time, as you do different things. We would like to observe you as you take care of your arthritis. This might include visits to healthcare professionals. You can ask, at any time, for an observation to stop, for the researcher to leave. As Heather will be spending several months in your community, she may observe you a few times. Before each time she will check to make sure that you are OK with the observation. The length of time Heather spends with you and what kinds of things she observes is entirely up to you. Her presence should not add to your daily demands. Heather will write down what she sees and hears so that she doesn't forget.

Privacy and Confidentiality

Because this research is taking place in your community and observations might include interactions will healthcare professionals, there is a risk to privacy and confidentiality. The researcher's presence while you are visiting a healthcare professional might change the way your visit unfolds. It may change things for the better (by having a second person to remember what is said) or for the worse (by making you or the healthcare professional uncomfortable). At any time during any observation you (and also the healthcare provider) may ask Heather to leave the area.

As well, there is a risk to maintaining confidentiality. Because Heather may be observing you in common areas, such as in the elder's group, other people in your community may know that you are taking part in the study. In order to maintain your confidentiality your name will not appear in the notes and all information that identifies you will be removed. Copies of the notes will be kept in locked cabinets. Data will be kept on computers that are password protected. Only Heather and her doctoral committee will have access to the data (once identifying information is removed).

After the study is complete you will be offered a copy of your interview transcript(s) and original tapes from your interview(s). If you do not want your data, it will be stored with all other data. The data may be used for future analysis and educational purposes. Five years after the study has been completed, all data stored by Heather will be destroyed as per UBC guidelines.

Results of the study will be reported in Heather's dissertation report, presented at conferences, published in academic journals, and in reports written for policy makers and healthcare decision makers.

For Further Information

If you have any questions or concerns about the observations or interviews, please contact Heather McDonald at xxx-xxx-xxxx or heather.mcdonald@xxx.ca. If you have any concerns about your rights or treatment while participating in this study, please contact the Research Subject Information Line in the UBC Office of Research Services at the University of British Columbia at 604-822-8598.

Consent

Your participation in this project is voluntary. YOUR DECISION TO PARTICIPATE OR NOT PARTICIPATE WILL IN NO WAY INFLUENCE YOUR HEALTHCARE. IF YOU DECIDE TO PARTICIPATE AND THEN CHANGE YOUR MIND, YOU ARE FREE TO WITHDRAW FROM THE PROJECT AT ANY TIME. THIS WILL IN NO WAY INFLUENCE YOUR HEALTHCARE.

Please check the appropriate boxes below.

Your signature below indicates that you have received a copy of this consent form for your records. Your signature indicates that you consent to participate in this study.

☐ I agree to be interviewed; ☐ I agree for the interview to be tape-recorded

☐ I agree to be observed caring for my arthritis

____

Signature Date

Please print name____

THE UNIVERSITY OF BRITISH COLUMBIA

School of Nursing
T201- 2211 Wesbrook Mall
Vancouver, B.C. Canada
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Tel: (604) 822-7417
Fax: (604) 822-7466

The Organization and Utilization of Arthritis Health Services for First Nations Peoples in the Southern Mainland Area of B.C.

Letter of Consent for Interview and Participant Observation (Healthcare Professionals)

Doctoral Candidate
Heather McDonald, PhD(c), RN, CRRN
UBC School of Nursing

Dissertation Committee Supervisor
Annette Browne, RN, PhD
Associate Professor
UBC School of Nursing

Co-Supervisor
Joan Anderson, RN, PhD
Professor Emeritus
UBC School of Nursing

Committee Members

Michael Marker, PhD
Associate Professor
Educational Studies, UBC

Rod McCormick, PhD
Associate Professor
Education and Counselling Psychology, and Special Education, UBC

Dr. Carol Jillings, RN, PhD
Associate Professor
UBC School of Nursing

You have been invited to participate in this study because you provide arthritis care services. This research is being conducted as part of the doctoral degree in nursing requirements for Heather McDonald.

Background

The need for redesign of the healthcare system to meet the needs of people with chronic illness has been well established. So has the need to create services that are accessible and effective for Canada's Aboriginal peoples who have long suffered a disproportionate burden of illness and disability relative to the overall Canadian population. Arthritis is a chronic illness for which many specialized health services have been created. However, the appropriateness and effectiveness of these services for First Nations peoples is not well understood. Indeed, B.C. government statistics show that First Nations people tend to use health services in ways that are different from the overall Canadian population. In B.C., First Nations people tend to be hospitalized much more than others for conditions that are usually managed in outpatient settings. Additionally far fewer homecare and rehabilitative care services are used by B.C. First Nations as compared to the overall B.C. population. In order to understand how well current arthritis services are working for First Nations peoples, and to provide recommendations for improvements in arthritis services if warranted, an in-depth look at how arthritis services are set up and used is required. During this study, both First Nations arthritis sufferers and arthritis services healthcare professionals will be invited to provide insight into the workings of the health system in this area.

Participation and Reporting

In order to learn more about how arthritis services are organized and delivered, Heather will be interviewing healthcare professionals. She will be asking you about your experiences providing care to First Nations arthritis sufferers and about what you think the strengths and weaknesses of the current system are. Interviews will occur at a time and location convenient to you and usually take between 20 and 60 minutes. Interviews will be tape-recorded, if you agree. Heather may also ask to observe you, if the opportunity arises, as you provide care to First Nations patients participating in this study. Observations usually take between 10 and 20 minutes depending on what you are doing and what you are comfortable with. These observations should not affect daily routines or add to your workload. Heather will write down what she sees and hears so that she doesn't forget. The information that Heather collects will provide insight into how arthritis services are organized and delivered and what changes can be made, if any, to improve services for First Nations peoples.

Privacy and Confidentiality

Because this research is taking place in a healthcare facility and observations will be made during interactions with patients, there is a risk to privacy. At any time during an observation you (or your patient) may ask Heather to leave the immediate area. As well, there is a risk to maintaining confidentiality. Because Heather may be interviewing you in the facility, other people at the facility may know that you are taking part in the study. In order to maintain confidentiality of the data no names will appear in the notes and all identifying information will be removed from transcripts. Copies of the notes/transcripts will be kept in locked cabinets in the office of the Doctoral Candidate and data will be kept on computers that are password protected. Only Heather and her doctoral committee will have access to the data (all identifiers removed).

The data from observations and interviews (with no identifying information from any of the participants) will be kept for a minimum of five years in accordance with the University of British Columbia research policy. The data may also be used for future analysis and educational purposes by Heather and all copies will be destroyed after such usage. Results of the study will be reported in Heather's dissertation report, presented at conferences, published in academic journals, and reports written for policy makers and health care decision makers.

For Further Information

If you have any questions or concerns about the observation or interview, please contact Heather McDonald at xxx-xxx-xxxx or heather.mcdonald@xxx.ca. If you have any concerns about your rights or treatment while participating in this study, please contact the Research Subject Information Line in the UBC Office of Research Services at the University of British Columbia at 604-822-8598.

Consent

Your participation in this project is voluntary. YOUR DECISION TO PARTICIPATE OR NOT PARTICIPATE WILL IN NO WAY INFLUENCE YOUR EMPLOYMENT. IF YOU DECIDE TO PARTICIPATE AND THEN CHANGE YOUR MIND, YOU ARE FREE TO WITHDRAW FROM THE PROJECT AT ANY TIME. THIS WILL IN NO WAY INFLUENCE YOUR EMPLOYMENT.

Please check the appropriate box below. Your signature indicates that you have received a copy of this consent form for your records *and* that you consent to participate in this study.

☐ I agree to be interviewed; ☐ I agree for the interview to be tape-recorded

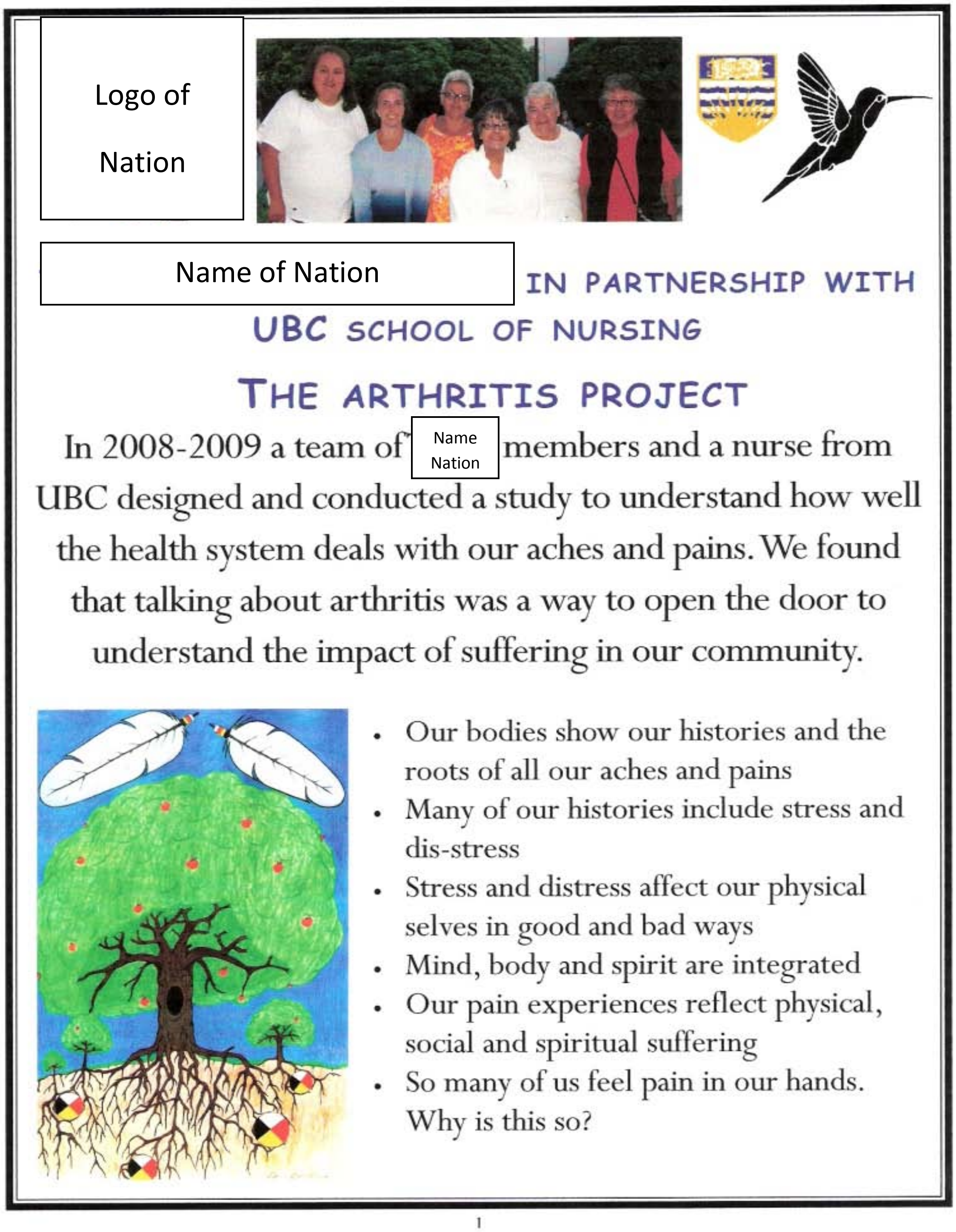
☐ I agree to be observed providing care to a First Nations patient participant

____

Signature Date

Please print name____

Appendix D: Knowledge Translation Handout for Community Participants



Logo of

Nation

Name of Nation

IN PARTNERSHIP WITH

UBC SCHOOL OF NURSING

THE ARTHRITIS PROJECT

In 2008-2009 a team of Name Nation members and a nurse from UBC designed and conducted a study to understand how well the health system deals with our aches and pains. We found that talking about arthritis was a way to open the door to understand the impact of suffering in our community.

- Our bodies show our histories and the roots of all our aches and pains
- Many of our histories include stress and dis-stress
- Stress and distress affect our physical selves in good and bad ways
- Mind, body and spirit are integrated
- Our pain experiences reflect physical, social and spiritual suffering
- So many of us feel pain in our hands. Why is this so?

1

THE ARTHRITIS PROJECT

The Power of Words

What messages about words and pain did we grow up with?

1. Sissies feel pain
2. Silence is strength
3. Don't talk about your suffering
4. Don't trust what you hear

How do you feel about these messages?

The Power of Dialogue

Talking about our pain and suffering can help us heal.

Not talking stops others from understanding what we're feeling.

Should everything be spoken?

Working with the health system

The health system focuses on the physical. It is well set up to do this but many of us don't use it. There are so many barriers.

What should we do about the barriers?
Does your doctor know about your pain?

We need also to look outside the system to heal our whole selves.

Where should we be looking?