

**Validation of the
Modified Health Assessment Questionnaire
In First Nations Persons with Rheumatoid Arthritis**

by

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Abstract

Background Standardized outcome measures used in assessment of chronic disease need to be relevant to the client if interventions based on the results are to be meaningful. The *Modified Health Assessment Questionnaire* (MHAQ) (Pincus, Summey, Soraci, Wallston, & Hummon, 1983) is an eight-item questionnaire used commonly with individuals with Rheumatoid Arthritis (RA) to assess self-reported function. This scale has been translated and validated in multiple languages and cultures but has never been evaluated for its relevance with a Canadian Indigenous population despite its frequent application in clinical and health research settings.

Purpose The primary objective of the following study was to determine whether or not the MHAQ is an appropriate measurement tool to adequately document the lived experiences of activity and participation in First Nations individuals diagnosed with RA.

Methodology A mixed methods sequential explanatory approach was utilized. The quantitative component consisted of secondary analysis of an existing clinical database developed at the University of Manitoba Health Sciences Arthritis Centre (UMHSAC). MHAQ scores and other indicators of disease activity of First Nations (n=252) and Caucasian (n=633) individuals with RA were examined for significant differences. The results informed a qualitative phase using interpretive description methodology whereby semi-structured interviews were held with 25 First Nations individuals with RA.

Results A significant relationship was observed between ethnicity and MHAQ score ($p < 0.001$) where the First Nations cohort demonstrated significantly higher scores in

pain and MHAQ scores ($p < 0.001$), as well as physician global assessment and morning stiffness ($p < 0.05$). Pain was the single greatest predictor of MHAQ score ($p < 0.001$). In contrast, a convergence coding matrix comparing MHAQ scores to first-hand narratives found only 65% agreement in responses. The thematic analysis of the qualitative component resulted in three key themes: *Ka-wachi-wa-pinaywin* (“Coldness in the bones”), *Adaptive Resilience*, and *Family Relations*.

Conclusion Concurrent validity of the MHAQ in a First Nations population was supported through statistical analyses but convergent validity was not supported by subsequent qualitative and mixed methods approaches. The assessment of disability requires an integrated approach that takes into consideration an individual’s personal context. Both barriers and facilitators in the environment, as well as personal factors, must be addressed.

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1. Introduction

Health measures at the population level have been in use for more than a century to indicate significant health problems faced by society; to contribute to policy development; and to monitor the outcomes of health and medical care (McDowell, 2006). Individual health measures have been used to assist in the diagnosis of a disease; evaluate treatment outcomes; predict future care needs; and to compare and contrast the health status between persons (Ibid.). Current health measures not only define health as an absence of disease and/or illness, but emphasize a person's ability or lack of ability to participate in a complex web of social, cultural and environmental situations (Bowling, 1997; McDowell, 2006). Assessing the impact of a health condition on an individual should be multidimensional; represent discrete domains; reflect the person's value systems; and expand beyond symptoms and activity limitations to include such broad concepts as social role participation (Davis, Wong, Badley, & Gignac, 2009; Davis et al., 2009; Fries, Spitz, Kraines, & Holman, 1980; Gignac, Cao, McAlpine, & Badley, 2011). Without taking into account the individual's meaning and value of that activity, health care providers, however, may unconsciously impose their own personal biases (Hewlett, 2003) and unintentionally take action which do not necessarily meet the needs and values of the patient.

The choice of tool to measure disease activity and its impact on an individual may reflect the clinician/researcher's perspective of health and disability. "Disability"^G in

the context of this study refers to impairments^G of body structures and functions, activity limitations^G and restrictions in participation^G (World Health Organization, 2001). “Functional status” refers to the general term from a rehabilitation perspective used to describe the completion of the activities of daily living (ADL), such a walking, dressing and getting in and out of bed. Additional guiding factors are the research question(s) and study design, including the ethical protection of participants, feasibility and accessibility to a particular population (Salazar, Crosby, & DiClemente, 2006). The outcome measure must not only capture what is of interest to the clinician/researcher, but must adequately capture what is meaningful to the individual respondent or participant (Carr et al., 2003; Frayne, Burns, Hardt, Rosen, & Moskowitz, 1996; G. H. Williams, 1987).

Historically, the measurement of the impact of disease focused on the results of a physical examination by a health care provider and available disease activity measures such as laboratory and radiological results (Liang, 1987). In the late 1960s, a shift occurred whereby the illness experience was recognized as distinct from the disease where “disease” refers specifically to the intrinsic pathology or disorder (WHO, 1980). Outcome measures of physical disability have evolved from self-care activities to more complex activities in the community; from a physical to a psychosocial perspective; from a clinician to a client focus; and from capacity^G in a controlled environment to actual performance^G in an individual’s own home environment (Gignac et al., 2011; Kidd & Yoshida, 1995).

Rheumatology is an example of a clinical practice and research area where this has been the case (Liang, 1987). Complex, lengthy and unreliable functional status scales for use with individuals with Rheumatoid Arthritis (RA) in the 1950s have evolved into more simple, valid and reliable client-focused tools (Helewa, Goldsmith, & Smythe, 1982). There is growing recognition of the need for the client's perspective in terms of disease activity and the impact it is having on activity^G and participation^G in the family and wider community setting (Pincus, 2005; Thompson, 1988; White, Wilson, & Keysor, 2011). This focus is consistent with the parallel theoretical development in disability studies and the recognition of a need to acknowledge and explore greater issues in the disablement process than that merely relegated to the physiological domains of an individual (Pincus, 2005; Thompson, 1988; Williams, 1987).

A wide variety of outcome measures are available for the assessment and on-going evaluation of persons with RA. The Stanford *Health Assessment Questionnaire* (HAQ) (Fries et al., 1980; Fries, Spitz, & Young, 1982) is often considered the "gold standard" in the measurement of functional status of persons with RA (Maska, Anderson, & Michaud, 2011) and is the most frequently used general functional measure in rheumatology (White et al., 2011). This self-administered tool first published in 1980 by James Fries from the Stanford Arthritis Center in California covers the five domains of disability, pain, the effects of medication, costs of care and mortality. A total of 41 questions assess difficulty over the past week with 20 specific activities of daily living (ADL). Eight functional categories include dressing, rising, eating, walking, hygiene, reaching, gripping, and errands/chores. Also addressed are the use of assistive devices

and receiving help from others. Because of the relative complex scoring system and length of the full HAQ, a shorter *Modified Health Assessment Questionnaire* (MHAQ) was developed in 1983 (Pincus et al., 1983) (Appendix 1). The number of questions was reduced from 20 to eight, while maintaining the eight categories of ADL and incorporating questions about perceived patient satisfaction and change in degree of difficulty with ADL; the use of aids or assistive devices was omitted (Maska et al., 2011; White et al., 2011).

In Manitoba, rheumatological clinical practice and research have relied heavily on the use of the MHAQ as evidence of change in functional status. Clinicians, at the University of Manitoba Health Sciences Arthritis Center (UMHSAC), use the patient-completed MHAQ to measure responsiveness to treatment and monitor change in activity related to RA over time. These data were entered into a clinical database and span a period of 1990 to current. From these data for the period 1990-2008, Peschken and colleagues (Peschken et al., 2010) showed the inequities in RA in Aboriginal Peoples⁶ in Manitoba. The term “Aboriginal” in the Canadian context includes First Nations, Inuit and Métis peoples (Royal Commission on Aboriginal Peoples, 1996). Investigators found that Aboriginal Peoples experienced higher rates of disease; younger age of RA onset (34 years compared to 43 years in Caucasian persons, $p < 0.001$) and significantly higher levels of pain, fatigue, and global disease activity. They also had significantly higher rates of disability as measured by MHAQ scores and Lansbury Index scores, a weighted joint count measure that considers the size of the joint (Lansbury, 1958). Subsequent UMHSAC studies found that first-degree relatives of Aboriginal

individuals with RA also experienced a higher prevalence of joint symptoms, explained in part by higher levels of RA autoantibodies such as anticitrullinated protein antibodies (ACPA) (Deane & El-Gabalawy, 2014a; El-Gabalawy et al., 2012; Smolik, Robinson, Bernstein, & El-Gabalawy, 2013). In a separate study, a link between age at first birth and higher prevalence of RA was determined, as well as the possible protective effect of multiple births (Peschken et al., 2012) While these studies improved understanding of RA onset, a major gap not addressed was whether the cross-cultural approaches to measuring disability held true in this population group. This study thus builds upon the work of these previous authors and focuses on the measurement of disability in First Nations peoples with RA, both by self-report as well as by health care providers.

Evidence has suggested that variability exists between self-report and performance-based measures of physical activity or functional status when controlling for race and/or ethnicity and socioeconomic status (Guillemin, Bombardier, & Beaton, 1993; Ren & Amick, 1998; Spencer, Albert, Bear-Lehman, & Burkhardt, 2008; Ware, Keller, Gandek, Brazier, & Sullivan, 1995). For this study, ethnicity does not only include race but the combined effects of culture, lifestyle, social factors, religion and collective community identity (Peschken, 2013). The validity and the relevance of the MHAQ have never been examined within a Canadian Aboriginal (or Indigenous Population¹) resulting

¹ Indigenous Populations refer to “communities, peoples and nations...which, having a historical continuity with pre-invasion and pre-colonial societies that developed on their territories, consider themselves distinct from other sectors of the societies now prevailing on those territories, or part of them. They form, at present, non-dominant sectors of society and are determined to preserve, develop and transmit to future generations their ancestral territories, and their ethnic identity, as a basis of their continued existence as peoples, in accordance with their own cultural patterns, social institutions and legal system” (United Nations, 2007). Within the Canadian context, Indigenous (or Aboriginal) Populations

in a significant gap in the evidence-based literature. An in-depth exploration into the impact of RA on the lived experiences of First Nations persons is therefore required where epidemiological studies suggest significantly higher rates of RA and gaps in appropriate service delivery may exist.

In the context of the current study, the terms “Indigenous” and “Aboriginal” are intended to include all original inhabitants of Canada. The author adheres to the term “Indigenous” as defined by the United Nations (2007) except in cases where the original source or reference has referred to “Aboriginal”. The term “First Nations” is used exclusively to reflect the original inhabitants of central and southern Manitoba, who self-identify neither as Métis or Inuit.

Research Objectives

The main research objective of the following study was to determine whether the MHAQ is an appropriate measurement tool to adequately document the impact of RA on the lived experience of activity and participation in First Nations individuals living in Manitoba. A related research objective was to investigate whether such a tool has relevance to First Nations individuals, particularly in relation to the current care model,

include First Nations (Indian), Inuit (akin to Alaskan Eskimo) and Métis (mixed ancestry) Peoples (Royal Commission on Aboriginal Peoples, 1996).

and to ascertain how issues of activity and participation of these individuals can be optimally addressed in both policy and direct service delivery.

Research Questions

In order to pursue the objectives described above, the following specific research questions were addressed:

1. What were the completion rates of the MHAQ in individuals with RA who self-identified as First Nations?
2. Was there a pattern in missing responses in the incomplete MHAQs?
3. Where there was complete information, how did the MHAQ scores correlate with other measures of disease activity in persons with RA who specifically self-identified as First Nations?
4. How was each of the eight individual items of the MHAQ interpreted by individuals from First Nations in terms of their own lived experience?
5. Were all eight individual items in the MHAQ meaningful to First Nations individuals?
6. What were areas of activity not currently captured by the MHAQ, both those that facilitated and hindered participation in the family and community?
- 7.** How could issues of activity and participation of First Nations persons living with RA in Manitoba be optimally addressed in the current care model, including both policy and direct service delivery?

Researcher's Perspective

The author's own clinical and research experiences with this population group facilitated clinical and administrative relevance of the study. The author spent more than five years in the late 1990s working as a physical therapist in the northern remote region where a portion of the qualitative component of this study took place. While working in neighbouring communities, she developed an understanding of the unique challenges that individuals with physical impairments face in maneuvering around their physical environment, participating fully in their community, and accessing services that are considered relatively commonplace in southern communities. These inequities led to her formal study of accessibility of services of First Nations people with disabilities as part of a Master of Science degree at the University of Manitoba in 1998. This study was a continuation of that research by exploring in more detail how the experience of disability is measured in individuals with RA and how those results manifest themselves in the management of the disease.

From this medical rehabilitation perspective, the term "functional status" refers to the general term used to describe an individual's ability to execute common activities of daily living such as walking. Where an original source uses the term "function" or "functional status" the use of that term is maintained where its alteration changes the original intent of the reference(s). Otherwise, the author has adhered to the term "function" only when the intent is to describe "body structures and functions, activity and participation" in combination (WHO, 2001).

2. Literature Review

2.1 Rheumatoid Arthritis

“Arthritis” describes a group of diseases and conditions that involve one joint or multiple joints, resulting in pain, swelling, stiffness and often joint deformity leading to decreased function. Rheumatoid Arthritis (RA) is characterized as a chronic progressive autoimmune disorder of unknown origin, characterized by symmetrical, erosive synovitis (inflammation of the lining of the joint) resulting in damage to the articular or bony joint surface and may include extra-articular manifestations (Aletaha et al., 2010a; Aletaha et al., 2010b; American College of Rheumatology Subcommittee on Rheumatoid Arthritis Guidelines, 2002; El-Gabalawy, 2005; Kvien, 2004; Neogi et al., 2010; Neogi et al., 2010). Symptoms can fluctuate over time resulting in “flares” that may necessitate a change in treatment or management (Bykerk et al., 2014). Joints commonly affected in RA include the metacarpophalangeal (MCP) joints (or “knuckles”), metatarsophalangeal (MTP) joints (base of the toes), wrists, shoulders, knees and hips. It is recognized that the pathogenesis of RA involves three processes: an immune response, an inflammatory response and an articular response (El-Gabalawy, 2005). These responses are mediated by both genetic (Deane, Norris, & Holers, 2010; El-Gabalawy, 2005; Peschken & Esdaile, 1999) and environmental factors (e.g., smoking) (El-Gabalawy, 2005; van Aken, van Bilsen, Allaart, Huizinga, & Breedveld, 2003).

The aggressive nature of RA leads to significant pain, joint destruction and limitations in physical activity, which in combination contributes to the high rates of

disability associated with the disease (Scott, 2002). Approximately 16% of individuals experience decreased activity after five years (Young et al., 2000) while limitations related to joint damage can continue to progress over a 20 year period (Kapetanovic et al., 2015). Disability related to physical, social and mental health domains, is a key component of outcome measurement and is recommended in the management and evaluation of all chronic disease, including RA (Fries et al., 1980). The ultimate goals of management of RA according to the American College of Rheumatology (ACR)(2002) are three-fold: prevent and/or control joint damage; reduce pain; and prevent loss of function. Achieving remission of the disease in recently diagnosed individuals is an additional goal. ACR guidelines for the assessment of disease activity in RA include subjective, physical (laboratory and radiographic), physician and patient global assessment, quality of life (QoL) measures and functional status (American College of Rheumatology Subcommittee on Rheumatoid Arthritis Guidelines, 2002). “Quality of life”^G in the context of this study represents the interplay between social, health, economic, and environmental conditions (World Health Organization, 2004), while “function”^G describes an inclusive term representing body structures and functions, activities and participation (WHO, 2001). Individuals themselves living with RA have identified pain, disability, fatigue and general feelings of wellness as important factors in the outcome of the management of their disease (Pincus & Sokka, 2003).

Epidemiology

The World Health Organization has reported global incidence rates of RA to be in the range of 20 to 300 per 100,000 people per year, with prevalence rates of 0.3 to 1% in most industrialized countries (American College of Rheumatology Subcommittee on Rheumatoid Arthritis Guidelines, 2002; Firestein, 2003; Kvien, 2004; Lillegraven & Kvien, 2007; Mikuls, 2003; World Health Organization, 2003). The recent Global Burden of Disease 2010 Study estimated global prevalence rates of RA to be closer to 0.24% (95% CI 0.23-0.25), with no significant change from 1990 rates (March et al., 2014). It has been reported that approximately 300,000 Canadians were affected by RA in 2011 (Bykerk et al., 2012). Lower prevalence rates have been reported for China and Japan (Silman & Pearson, 2002), while higher rates of 2- 6.8% have been reported in North American Indigenous populations (Barnabe, Elias, Bartlett, Roos, & Peschken, 2008; Deering, Lix, Bruce, & Young, 2009; Del Puente, Knowler, Pettitt, & Bennett, 1989; Elliott, Johnson, Leff, & Day, 2000; Ferucci, Templin, & Lanier, 2004; Peschken & Esdaile, 1999; Silman & Pearson, 2002).

In Europe, RA may not have been prevalent until the 17th century, while it existed among Indigenous North American populations several thousand years earlier (Rothschild & Woods, 1990). Over the last 20 years, higher rates of RA among various North American tribal groups have been documented, including the Tlingit Indians in Southeast Alaska (Boyer, Templin, & Lanier, 1991; Templin et al., 1994), Yakima Indians of Central Washington (Beasley, Willkens, & Bennett, 1973), Pima Indians of Arizona

(Del Puente et al., 1989), Nuu-Chah-Nulth Indians of the Pacific Northwest (Atkins et al., 1988), Chippewa Indians of Wisconsin (Elliott et al., 2000) and Cree and Ojibway of Manitoba (Peschken et al., 2010). These higher prevalence rates have been explained by genetic factors (DRB1 shared epitope and HLA-DR4 alleles in particular) (Deane et al., 2010; El-Gabalawy, 2005; Ferucci et al., 2004; Peschken & Esdaile, 1999), while the severity and burden of illness is multifactorial (such as larger joint involvement, and limited access to newer biologic medications) (Peschken et al., 2010).

Of particular relevance to the current study, persons identifying themselves as “Aboriginal” in the University of Manitoba Health Sciences Arthritis Centre longitudinal study (1990-2008) (Peschken et al., 2010) experienced younger age of onset of RA (34 years compared to 43 years in person identifying themselves as “white”, $p < 0.001$) and significantly higher levels of pain, fatigue, and global disease activity. The terms “Aboriginal” and “white” were two options among a list that also included Black, Hispanic and Asian. In Manitoba, Aboriginal peoples represent 16.7% of the overall population (Statistics Canada, 2013) and are primarily of Cree, Ojibway, Oji-Cree, Dakota, Dene or of Métis descent (Hallett, 2006). The data showed significantly higher rates of disability among the Aboriginal cohort compared to the white (or Caucasian) cohort measured by MHAQ scores (Pincus et al., 1983) and Lansbury Index scores, a weighted joint count that considers the size of the joint, where larger joints are acknowledged to play a greater role in function (Lansbury, 1958). Greater rates of disability in these persons are suggested to be partially explained by larger joint involvement, particularly knees and elbows; biologic phenotype; limited access to more

aggressive medications under the federally funded *Non-Insured Health Benefits Program*²; geographical hardship in terms of accessing regular specialist care; high smoking rates; or other unknown factors (Peschken et al., 2010).

The systemic inflammatory nature of RA can also affect the brain, liver, lungs, exocrine glands, muscles, and bones (McInnes & Schett, 2011). Co-morbidities common among people with RA include cardiovascular disease, infection, osteoporosis, lymphoproliferative malignancy and peptic ulcer disease (Cioffi et al., 2015; Mikuls, 2003; Pinheiro, Souza, & Sato, 2015; Schau et al., 2015) as well as an increased risk of fracture (Michel, Bloch, & Fries, 1991). The number of co-morbidities experienced by individuals with RA has also been directly linked to an increased risk of premature death before age 75 (Mikuls, 2003), possibly related to cardiovascular disease secondary to chronic systemic inflammation (Maradit-Kremers, Nicola, Crowson, Ballman, & Gabriel, 2005; Symmons, 2005). The Rochester Epidemiology project in Minnesota, USA, has reported an increasing mortality gap with standardized mortality rates of 3.8 per 100 person-years for those with RA compared to 1.35 without RA between the years 1965 and 2000 in the US (A. Gonzalez et al., 2007).

The economic burden associated with RA is significantly high (Kvien, 2004; Maetzel et al., 2004; Public Health Agency of Canada, 2010). It has been reported that in

² The Non-Insured Health Benefit (NIHB) Program provides a limited range of medically necessary health-related goods and services not provided through private insurance plans, provincial/territorial health or social programs or other publicly funded programs to those individuals recognized under the *Indian Act* of Canada (First Nations and Inuit Health Branch Health Canada, 2011; Health Canada, 2008). Such goods and services include a specific inventory of drugs, dental care, vision care, medical supplies, medical transportation, traditional healers, and short-term crisis intervention (Health Canada, 2011).

Canada, the indirect and direct costs related to arthritis alone totaled more than 6.4 billion dollars in the year 2000 (Public Health Agency of Canada, 2010). In Ontario in the same time period, the indirect costs related to RA were up to five times higher than indirect costs related to osteoarthritis or high blood pressure, or both (Maetzel et al., 2004).

Risk factors

Factors associated with an increased risk of developing RA include age, gender, genetic factors (DRB1 and HLA-DR4 alleles in particular), obesity, a high consumption of red meat and/or decaffeinated coffee, a previous blood transfusion, air pollution, silica exposure and adverse pregnancy outcomes (Deane et al., 2010; Symmons, 2005; van Aken, van Bilsen, Allaart, Huizinga, & Breedveld, 2003; van Aken et al., 2003). Strong associations between RA and cigarette smoking have been well established (El-Gabalawy, 2005) while the onset of RA has been associated with adverse life events (McInnes & Schett, 2011). In contrast, protection from developing RA may occur from oral contraceptives and sufficient amounts of fruit and Vitamin C consumption (Deane et al., 2010; Symmons, 2005), as well as giving birth to multiple children (Peschken et al., 2012).

Management

Early referral and treatment is recommended practice for suspected RA (American College of Rheumatology Subcommittee on Rheumatoid Arthritis Guidelines,

2002; O'Dell, 2002; S. Oliver, 2003; Tavares et al., 2013; Wakefield et al., 2000). In the longitudinal study of the Early Arthritis Clinic study in Leiden, Netherlands, researchers reported that assessment by a rheumatologist 12 weeks or later after diagnosis was associated with 1.3 times higher rates of joint destruction over six years. Only 31% of patients in their study met the criteria of rheumatology referral in less than 12 weeks (van der Linden et al., 2010). Emery et al (2002) recommended that early referral to rheumatology be made if an individual presents with three or more swollen joints; or the duration of morning stiffness is greater than 30 minutes; or where the metatarsophalangeal (MTP; base of the toes) or metacarpophalangeal (MCP; knuckles of the hand) joints are involved. The authors state that primary health care providers should not be misled by laboratory and radiological findings, which are often absent or inconclusive in early RA (Emery et al., 2002). Not following closely the clinical practice guidelines for RA, the lack of early referral to rheumatology specialists, and the late initiation of disease-modifying antirheumatic drugs (DMARDs) have been identified as risk factors for increased joint deformity, joint destruction and loss of function (van Aken et al., 2003). Timely referrals to rheumatology and quality of care appear to be strongly related to physician rapport, patient preferences, access issues, clinical and administrative leadership, physician confidence and expectations (Suter, Fraenkel, & Holmboe, 2006). These authors recommend increased emphasis on clinical practice guidelines as one component of improving quality care.

The ultimate goals of medical management of RA are three-fold: prevent and/or control joint damage; prevent loss of function; and reduce pain (ACR, 2002). Specific

therapies should be used to suppress synovial inflammation and joint erosions based on the pathogenic mechanisms (Firestein, 2003). Management should include early initiation of DMARDs, such as Methotrexate, Hydroxychloroquine, Cyclosporine or Sulfasalazine within 12 weeks of disease onset; possibly nonsteroidal anti-inflammatory drugs (NSAIDs); possibly steroidal joint injections and/or low-dose oral steroids; education to the individual and his/her care giver(s); and referral to occupational therapy, physical therapy, social work and/or health educators (ACR, 2002). Where there is inadequate response to therapy after three months of maximal treatment, DMARDs should be altered, including switching to other monotherapies, combination therapies or biologic therapies, such as Enbrel, Humira, Remicade or Rituxin (Ibid.).

Interprofessional management geared at joint protection, energy conservation techniques, suitable aerobic activities, joint range of motion and strengthening exercises are important measures in maintaining joint mobility, strength and endurance (American College of Rheumatology Subcommittee on Rheumatoid Arthritis Guidelines, 2002; Callahan et al., 2008; Conn, Hafdahl, Minor, & Nielsen, 2008; Forestier et al., 2009). These interventions may include but are not limited to exercise (Callahan et al., 2008), protective splints (Veehof, Taal, Willems, & van de Laar, 2008), acupuncture (Hughes, 2009), and therapeutic footwear (Williams, Nester, & Ravey, 2007).

Education in self-management facilitates self-efficacy, or self-confidence, in the ability of an individual to manage the disease, as well as accessing care appropriately (S. Oliver, 2003). Types of self-management used by individuals with arthritis include taking

medications, using other treatments (heat, ice, yoga, rest) and seeking support from friends or family (Katz, 2005). Where there is limited access to an interprofessional team due to limited resources, whether human and/or financial, alternative care models including telehealth, patient-initiated care and expanded roles for health care professionals should be considered (Vliet Vlieland, Li, MacKay, Bombardier, & Badley, 2006).

The Canadian Rheumatology Association (CRA) has compiled five overarching principles in the general management of RA (Bykerk et al., 2012):

1. Patients with RA should be cared for by a rheumatologist or by other healthcare professionals trained and experienced in RA diagnosis, clinical assessment, and appropriate prescription of RA drug therapies;
2. Every Canadian with RA should have timely and equal access to appropriate rheumatologic care;
3. Treatment of patients with RA should be based on shared decision-making between patient and physician. This should include provision of appropriate RA education materials to patients and caregivers and clear discussion of the benefits and potential risks of treatment;
4. The development of shared-care models with primary care physicians and/or other allied health professionals trained in musculoskeletal conditions could enhance healthcare delivery for patients with RA;
5. RA healthcare providers should consider opportunities for engaging patients in research both as participants and as potential research partners/consumer representatives to further the knowledge and understanding of RA.

The CRA acknowledges the significant progress made in the last decade in the pharmacologic management of RA in Canada, with earlier and aggressive DMARDs and

the introduction of biologic drugs targeting specific mechanisms of inflammation (e.g., tumor necrosis factor inhibitors) (Ibid.) Their 26 recommendations for management and treatment are intended to promote best practices and improve healthcare delivery for those persons with RA in the Canadian context.

Manitoba Context

For individuals living in Manitoba with RA, diagnosis and management of the disease typically occur first at the primary care level followed by a timely referral to a rheumatologist. Primary care is typically delivered by a family physician, but in northern and remote communities, a nurse working in an expanded scope of practice more often delivers care. A limited number of family doctors augment the care provided by these nurses, and in some cases, itinerant physiotherapists, pharmacists, dieticians and medical specialists also play an active role. Referral to an urban-based specialist is an option but must be medically justified, particularly for First Nations whose travel costs are covered by the Health Canada Non-Insured Health Benefits Program (NIHB). In the context of this study, the initial assessment and reassessment by a rheumatologist can drive the management options available to an individual with RA, particularly for those eligible for Non-Insured Health Benefits. In order to receive the pharmaceutical benefit of the newer biologic drug regime for example, rheumatologists must submit evidence to the NIHB Program of the effectiveness of such medications on an individual basis. Efficacy is based on tender and swollen joint counts; Patient and Physician Global

Assessments (PGA & MDGA respectively); and acute-phase reactants, such as erythrocyte sedimentation rate (ESR) and C-reactive protein (CRP) levels.

Impact on physical activity and participation

The aggressive nature of RA leads to significant pain, joint destruction, activity limitations and restrictions in participation, where it has been reported that approximately one third of individuals require surgery within 10 years (Kvien, 2004) and approximately 90% have some degree of disability within two decades of onset (Emery et al., 2002). The World Health Organization (2003) has reported that work capacity is affected in most persons with RA within five years of onset of symptoms. It has been estimated that about one quarter of individuals with RA experience work disability six years after the onset of the disease, increasing to roughly half after 20 years (Wolfe & Hawley, 1998). In contrast, it has been recently reported that individuals in the Canadian Early Arthritis Cohort (CATCH) study were found to experience improved functional status and reduced disease activity over a two-year period after early initiation of treatment (Boyd et al., 2013). The authors considered this result a reflection of more aggressive treatment strategies available now than a decade ago.

It has been acknowledged that the relationship between disability and the damage visible on radiographs in individuals with RA is complex (Scott, 2002). While it takes approximately five years for a significant relationship to appear, 25% of the disability can be accounted for by joint damage. Poor outcome of individuals with RA has been linked to multiple active joint involvement (more than 20 joints); higher acute-

phase reactants (ESR and CRP); positive rheumatoid factor (RF); early joint erosions detectable on radiographs; limitations in functional status at disease onset; younger age at onset; and lower education and socioeconomic status (American College of Rheumatology Subcommittee on Rheumatoid Arthritis Guidelines, 2002; Scott, 2002).

2.2 Measurement of disease activity and disability related to Rheumatoid Arthritis

Theoretical Bases and Evolution of Functional Status Assessment Measures

An assessment of an individual in the health care context is done for three main reasons (Kane, 2000). First, the assessment findings can assist in the diagnosis, thereby guiding treatment: what will be done, when and where (hospital or community). Secondly, the assessment findings may help determine eligibility for services, for example, whether costs of care will be paid by a third party. Lastly, findings may be used for program evaluation purposes or to assess the effectiveness of care. Assessments ultimately evaluate two things: positive and negative risk factors of a health condition and the outcome of an intervention. If optimization of activity and participation are two of the primary goals of intervention, then measures of disability must reflect meaningful engagement of persons within their determined social roles and broader community. Without relevance to the individual's experience, key information may be missing or lost. Participation in social roles includes relationships with family, employment,

community interactions, and pursuing leisure activities. “Role participation”⁶ has been defined as “involving broad patterns of purposeful behavior at the level of societal involvement. Roles consist of acts and tasks, but because of their range and diversity, cannot be constrained to a universal list of these acts and tasks. Instead, they are dependent upon context and their assessment is largely subjective” (Gignac et al., 2008, p. 1656). This emphasis on the individual’s perspective has not always been the focus.

The evolution of functional status measures since the 1950s has been described as a transition from a clinician to a client focus; from a physical to a psychosocial perspective; from self-care activities to more complex activities in the community (Gignac et al., 2011; Pincus, 2005; Thompson, 1988; Williams, 1987); and from capacity (what an individual is observed to do in a standardized environmentally-adjusted situation) to performance (what an individual does in his/her current environment) (World Health Organization, 2001). The role of the environment as a “scene setter” and personal motivation or volition is recognized as contributing to the differences in these abilities (Badley, 2008). Complex, lengthy and unreliable functional status scales have evolved into more simple, valid and reliable client-focused tools (Gignac et al., 2011; Helewa et al., 1982).

In rheumatology, outcome measurements have historically been based on the findings of a physical examination and review of laboratory results, with a focus on the pathology of the disease (Liang, 1987). This biomedical approach to the measurement of disease and disability emphasizes the disease trajectory from etiology to pathology to

manifestations of a disease that leads to “abnormal” functional status. In the case of RA, the autoimmune response equates to the etiology; recurrent synovitis and joint damage represent the pathology; and pain, joint deformity and loss of agility are the manifestations. This theoretical linear approach to disability, however, fails to acknowledge any contextual factors in the manner in which manifestations of the underlying pathology develop and/or are sustained.

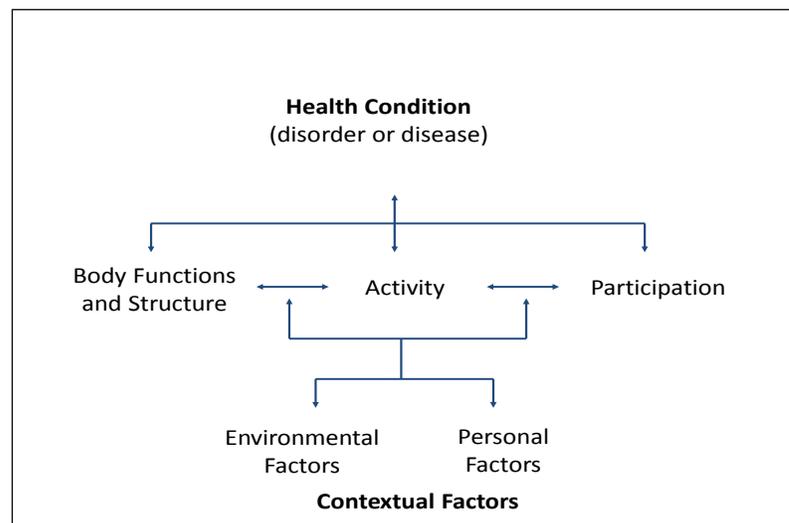
The notion of deviation from “normality” found in traditional biomedical approaches has been criticized by disability rights advocates as representing persons with disabilities as lacking capacity and requiring care (Bickenbach, Chatterji, Badley, & Üstün, 1999). An alternative approach to this view of disease and disability is the “social disablement” model developed by the American sociologist, Saad Nagi, in the 1960s (Verbrugge & Jette, 1994). This paradigm views disability as a problem created by a complex set of conditions, many of which are created by society (Jette & Keysor, 2003; Verbrugge & Jette, 1994). Disability represents the gap between a person’s capabilities and the demands created by his/her social and physical environment, where laws and policies are needed to remove exclusionary barriers (Shakespeare, 2005a). It is acknowledged that not all impairments lead to disability and that the experience of disability is shaped by the individual's reaction; the reaction of others surrounding the individual (including family, friends, employers, and health care professions); and the environment, both physical and socio-cultural. Social change is the main issue, while management of the disability requires social action, that is, modifications to the environment in order to permit full and equal participation in society. Functional

limitations are distinguished from disability by the authors where the former refers to an individual's capability free of situational context, while "disability refers to the expression of a functional limitation in a social context" (Verbrugge & Jette, 1994). Life activities are suggested as falling into three categories: obligatory (required for survival and self-sufficiency, such as self-care); committed (associated with primary social roles, such as child care); and discretionary (such as exercise and hobbies) (Verbrugge, 1990, as cited in Katz, Morris & Yelin, 2006). Jette (2006) described "functional limitations" as representing restrictions in a person's performance. In the case of RA, difficulty with walking, bending, making a fist and getting dressed are examples of functional limitations. Elevated levels of ESR and CRP, the presence of RF, and recurrent synovitis represent active pathology and joint swelling and deformity are the impairments. The inability to take public transportation, work, or care for an infant is an example of the disability resulting from arthritis. From a social disablement^G lens, disability is neither a single medical problem nor only the result of social oppression; disability is the product of the ongoing interface between impairments of the body and the environment preventing full participation (Shakespeare, 2005b).

Another alternative to the biomedical approach to disability is represented in the biopsychosocial model (Figure 1), the framework for the World Health Organization's *International Classification of Functioning* (ICF) (World Health Organization, 2001). The ICF identifies contextual factors as playing a significant role in the manifestation of the activity limitations and participation restrictions of the person, an effect recently supported empirically using Structural Equation Modeling (Rouquette et al., 2015). The

ICF explicitly differentiates activity on the individual level from participation in a person's broader family and community setting, mediated by both personal and environmental factors. These personal and environmental factors include culture, attitudes, the built environment as well as the structure of local health and support services. The double arrows in the model are intended to acknowledge the interaction between the various components.

Figure 1. Biopsychosocial Model of the ICF



Reproduced, with the permission of the publisher, from *the International Classification of Functioning, Disability and Health (ICF)*. Geneva, World Health Organization, 2010 (Fig, p. 9)
<http://www.who.int/classifications/icf/training/icfbeginnersguide.pdf>, accessed July 12, 2015.

One of the challenges facing the measurement of activity and participation is that different people may act and complete tasks differently with apparently similar impairments (Badley, 2008; Bowling, 1997). The difference in performance will depend on personal expectations, priorities, goals, social support networks, the built

environment, technical aids and adaptations. Many of the functional scales currently used are not sensitive enough to capture the nuances and breadth of functional ability, asking the individual for example *if* he/she can do the activity instead of *when* the person last did the activity, or *how* he/she did the activity. Results of such measures can lead the health care provider to false assumptions about the current impact of the condition, such as RA, which can in turn influence the intervention(s). The social disablement framework and the biopsychosocial model of the ICF both recognize that the individual and social circumstances impacting activity and participation demand a sensitive and responsive means of addressing limitations and restrictions. An integrative model is required to address activity and participation in its broadest context while still accounting for medical intervention addressing the actual impairment (Thomas, 2004).

The extent to which practicing rheumatologists actually use integrated outcome measures in their daily clinical practice, however, remains unclear despite existing recommendations by the ACR (American College of Rheumatology Ad Hoc Committee on Clinical Guidelines, 1996; American College of Rheumatology Subcommittee on Rheumatoid Arthritis Guidelines, 2002). A survey of all practicing rheumatologists in the United States was conducted to ascertain their clinical use of health related quality of life (HRQOL) scales (Russak et al., 2003). Of the 493 respondents (representing a response rate of 14%), 48% reported that none of their patients completed such self-reports. The majority (63%) reported that such information was “somewhat valuable”; 14% said it was “not of any value”. The principal reason given for non-utilization was the

lack of staff time. Where such limits in time are the main deterrent to the use of outcome measures, self-report tools present a viable option worthy of consideration.

In choosing a relevant clinical assessment tool, it is important to consider that many persons living with a disability view disability strictly in terms of their own personal daily limitations and restrictions, while others may view it as a sociopolitical issue. This perspective distinguishes the traditional biomedical approach from the social model of disability (Oliver, 1998) as described above. Biomedical approaches to disability are based on a positivist approach, focusing on cures, the reduction of impairments, or the evaluation of clinical trials. Many existing health indicators have been critiqued as reflecting an overemphasis on a disease model or medical model of health status (Bowling, 1997). Alternatively, in social constructionism theory, subjectivity and experience are viewed as essential while critical theory views disabling barriers as the key issue (Oliver, 1998). Available evaluation tools used in clinical care and research reflect the evolution of these different theoretical approaches to disability. The choice of tool ultimately represents the perspective that the clinician/researcher brings to the encounter. This dynamic is explored further in the next section.

Assessment Measures

Initial and repeated assessments of disease activity, drug toxicity, and treatment effectiveness are essential in the diagnosis and on-going management of RA (American College of Rheumatology Ad Hoc Committee on Clinical Guidelines, 1996). A large

number of evaluation tools are available to assist clinicians in this endeavor and a partial list is presented in Appendix 2. Although lengthy, Appendix 2 is not meant to be an exhaustive list; the reader is also directed to the Special Issue on Patient Outcomes in Rheumatology in the Journal *Arthritis Care and Research* (2011) for a detailed review of over 250 outcome measures currently in clinical use. The wide assortment of assessment tools reflects the fact that there is no single “gold standard” measure of disease activity for RA nor its impact on the individual (Pincus & Sokka, 2003; Pincus, Yazici, & Sokka, 2007). Some tools are specific to RA while others are generic and are indicated thus. The generic tools allow for easier comparison between diseases, while the RA specific tools may address specific issues common to RA (Kane, 2000; Lubeck, 2002). Disease-specific assessments may also be more sensitive to change over time (Lillegraven & Kvien, 2007) as generic measures may demonstrate floor and ceiling limitations, which can limit the meaningfulness of the findings in some settings or populations. That is, substantial numbers of people get the lowest possible score on an assessment measure (floor effect) or the highest possible score on an assessment measure (ceiling effect) (Ware & Sherbourne, 1992). This results in an inability to capture the upper or lower extremes of some problems. In contrast, condition-specific measures highlight specific effects of a problem and tend to measure clinically meaningful changes of a specific condition (Kane, 2000). It has been suggested that the two types of measures be used in combination to optimize the value added by both approaches.

The assessment tools in Appendix 2 are listed in groupings based on typology addressing disease activity; quality of life; pain; activity and participation; and “other”, which generally represent a combination or an individual component of a larger scale or index. Some assessment tools, such as the Arthritis Impact Measurement Scales (AIMS) (Meenan, Gertman, & Mason, 1980) and the Stanford Health Assessment Questionnaire (HAQ) (Fries et al., 1980) are commonly used to assess multiple domains, such as quality of life and pain as well as physical and mental health. The measures can be further subdivided into the perspective of the health care provider or the perspective of the client (self-report), or in some cases, the combination of the two, such as the Modified Disease Activity Score (Modified DAS-28) (Prevoo et al., 1995), the Core Sets of the International Classification of Functioning (ICF) (Stucki et al., 2004; Stucki & Cieza, 2004; World Health Organization, 2001), and the Simplified Disease Activity Index (SDAI) (Smolen et al., 2003).

Measures of Disease Activity

Assessment tools that evaluate disease activity in persons with RA are all specific to RA. Examples of early disease activity assessment tools used in rheumatology include the Steinbrocker Therapeutic Scorecard (Steinbrocker & Blazer, 1946), the Lansbury Index (Lansbury, 1958), and the Ritchie Index (Ritchie et al., 1968). These tools are based principally on the physician’s perspective, consistent with the traditional medical model, where etiology leads to pathology, which results in clinical manifestations of the disease and/or illness, based on normal standards. Scores and /or ratings are based primarily on

the physician expert observations and clinical findings, with or without augmentation by a client report.

More recent disease activity assessment tools have included the client's perspective, consistent with an increasing emphasis on the impact of the disease on the individual. These recent disease activity measurement tools include the Rapid Assessment of Disease Activity in Rheumatology (RADAR) (Mason et al., 1992); the ACR Core Data Set (Felson et al., 1993); the Disease Activity Score (DAS) (van der Heijde, van 't Hof, van Riel, & van de Putte, 1993) and the modified DAS-28 (Prevoo et al., 1995); the Rheumatoid Arthritis Disease Activity Index (RADAI) (Stucki, Liang, Stucki, Bruhlmann, & Michel, 1995); and the Simplified Disease Activity Index (SDAI) (Smolen et al., 2003). Only the RADAR and the RADAI rely solely on the report of the client to determine disease status. Nevertheless, all of these tools include the client's perspective, generally in the form of a "patient global assessment" (PGA) rating. The PGA question is a derivative of the following statement: "Considering all ways in which illness and health conditions may affect you at this time, please make a mark on the (10 cm) line below to show how well you are doing." In contrast, the physician global assessment (MDGA) asks "How would you rate the patient's arthritis and how it affects him/her today?" (Fired et al., 1980).

While high levels of ESR and CRP are strong indicators of disease activity and rheumatoid factor (RF) positivity is predictive of future joint disease (Paulus & Bulpitt, 1995), the ACR reports that patient/client self-reports are an effective means of measuring decreased functional status and predicting work disability, costs and

premature mortality (Pincus, 2005). When the correlation between PGA and MDGA is poor (ICC = - 0.172), the patient and the physician are likely measuring different domains (Rohekar & Pope, 2009). Patients may be responding from the perspective of their own “subjective” experiences of pain, fatigue, and social participation, while the physician may be responding from the perspective of “objective” laboratory data and their own clinical observations (Ibid.).

At a population level, such tools informed by a biomedical framework can provide reliable and valid tracking of disease trends regionally, nationally and internationally, and may help inform program planning and evaluation. At an individual level, such tools aid monitoring RA disease progression and the efficacy of treatment interventions. An earlier diagnosis and such monitoring may help reduce client anxiety and uncertainty (Bury, 1991). However, biomedically informed disease activity measurement tools are criticized for promoting health care providers as gatekeepers to limited and valuable resources (e.g. medications and needed services) (Rothman, 2010). This approach is critiqued for perpetuating a dependency relationship between persons with disabilities. In other words, the medical experts and providers are placed at the centre of the system, determining welfare and disability benefits (Finkelstein, 1993; Rothman, 2010). Injustices can occur when disability is overmedicalised (Shakespeare, Iezzoni, & Groce, 2009), whereby structural issues contributing to health status, poverty, environmental barriers, and isolation are ignored. In contrast, proponents of this approach suggest that limited resources require some form of rationalization, and that

biomedically informed measures of disease activity provide a standardized evaluation approach to inform equitable distribution of goods and services.

Measures of Quality of Life

“Quality of life”^G (QoL) measures move beyond the typical and capture the interplay between social, health, economic and environmental conditions that affect human and social development. This concept is broad-ranging, incorporating a person’s physical health, psychological state, level of independence, social relationships, personal beliefs and relationship to the environment (WHO, 2004). QoL measures describe the overall impact of an illness and an individual’s response to these impacts (de Jong, van der Heijde, McKenna, & Whalley, 1997).

A number of QoL measures are listed in Appendix 2. They are grouped as generic and RA specific. Some provide a single global score (a health index) while others describe a number of dimensions (a health profile) (Carr, Thompson, & Kirwan, 1996). The Sickness Impact Profile (SIP) (Bergner, Bobbitt, Pollard, Martin, & Gilson, 1976) is the oldest measure. It is a generic instrument completed by the health care provider, covering the domains of mobility, emotions, social, sleep, nutrition, work, household, communication, leisure, cognition, and hygiene. This comprehensive tool allows comparison with other diseases. It is unclear however, what bias the health care provider may bring to the scoring. All subsequent QoL instruments in Appendix 2 are completed by the client/patient. While saving the clinician the time needed for test administration, the individual is given the opportunity to self-assess the impact that RA

has had on his/her life, albeit within the dictated confines of the instrument. Three measures all published in 1980 are commonly used to measure QoL: the Nottingham Health Profile (NHP), a generic tool measuring physical, psychological, social, pain, energy, role and sexual activity domains (Hunt et al., 1980); the Arthritis Impact Measurement Scales (AIMS) specific to arthritis (but not RA), measuring the impact on physical, emotional and social health, pain, anxiety and depression (Meenan et al., 1980); and the Stanford Health Assessment Questionnaire (HAQ), addressing issues of death, function, discomfort, drug toxicity and costs (Fries et al., 1980). The HAQ is perhaps unique in addressing issues of costs related to the disease. The original AIMS was modified into the AIMS2 in 1992, with the addition of questions pertaining to arm function, work, and social support (Meenan, Mason, Anderson, Guccione, & Kazis, 1992). The McMaster Health Index Questionnaire (MHIQ) (Chambers, Macdonald, Tugwell, Buchanan, & Kraag, 1982) and the Rheumatoid Arthritis Quality of Life (RAQoL) scale (de Jong et al., 1997) were subsequent disease-specific additions to the choice of QoL instruments, measuring domains similar to those previous, while the Medical Outcomes Study (MOS) 36-item Short-Form Health Survey (SF-36) provided another generic instrument option (Ware & Sherbourne, 1992). The RAQoL questionnaire developed in Europe offers the additional dimension of physical contact and is the only instrument to explicitly declare a theoretical basis: “life gains its quality from the ability and the capacity of the individual to satisfy his or her needs” (de Jong et al., 1997). These authors define QoL as “the extent to which Rheumatoid Arthritis interferes with the patient’s ability to fulfill his or her needs”(de Jong et al., 1997).

Lubeck (2002) suggests that the HAQ, the AIMS, and the MOS SF-36 are all acceptable tools with which to measure health-related quality of life (HRQoL) in persons with RA. In contrast, the AIMS and AIMS2 have been criticized for their length, lack of available response options, and possible lack of sensitivity over time (Tijhuis et al., 2001). The RAQoL authors (de Jong et al., 1997) criticize the use of the AIMS, NHP and the MOS-36 to measure QoL, as they feel that these instruments actually measure health status, addressing issues of impairment^G, disability^G and handicap^G, not QoL. Indeed, Bowling states that the NHP was never intended by its developers to measure HRQoL (Bowling, 1997). The AIMS was also criticized for being developed without the expertise of the clients themselves, while the development of the RAQoL was based on qualitative interviews with persons with RA informing item generation. Interestingly, the construct validity^G of the RAQoL was established by comparing the instrument with the NHP (Hunt et al., 1980), an instrument whose item generation was also developed without medical expertise. The RAQoL authors advocate the use of HRQoL measures for patients with RA, because the HRQoL can assess the unique impact of health status and the interaction between health status and other influences on a person's life.

The argument that the RAQoL authors bring forward adds an interesting dimension to the theoretical perspective of evaluation and models of disablement. When an assessment tool such as those purporting to measure QoL are developed by medical experts in the field, those tools are arguably upholding the biomedical approach to the measurement of health status and its impact on an individual's life. Moreover, biomedical centering is further maintained when the content and construct validation of

a tool is judged only by comparison against existing measures developed by medical experts. An approach more consistent with the social disablement model, however, would advance the development of instruments that centre on participant's meaning of QoL (Oliver, 1998). Proponents of this approach would ask how does the environment create barriers to social interaction? This approach not only addresses mobility restrictions and QoL. It also acknowledges the role of the environment and the hindering aspects that it may present.

In summary, QoL measures are critiqued for medicalizing an intensely personal construct, such as relationships and social activities that are not necessarily amenable to medical intervention (Carr, Thompson, & Kirwan, 1996). Alternatively, proponents of measuring QoL, acknowledge the impact that QoL indicators may have on health status and suggest that the health care provider may play a valuable role as "gatekeeper" to needed interventions that may in turn address any gaps identified in the QoL measure. Clinicians and researchers are thus challenged by how to meaningfully fit a social construct into a biomedical encounter.

Measures of Pain

Other outcome measures focus on pain, which is "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage"(International Association for the Study of Pain as cited in Sokka, 2003). Chronic pain is associated with age, ethnicity and socioeconomic status of an individual, decreased quality of life, disability and high levels of health care utilization,

where “chronic” pain is defined as pain lasting more than three months (Green & Hart-Johnson, 2010; Meana, Cho, & DesMeules, 2004). The burden of pain appears greater for women than men, possibly related to age, income, education, psychological processing of pain and societal, family and occupational roles (Meana et al., 2004). Pain is also described in terms of location, frequency, duration, quality, and severity (Lichtenstein, Dhanda, Cornell, Escalante, & Hazuda, 1998), via such terms as “pain”, “hurt”, “sore” and “ache” (Gaston-Johansson, Albert, Fagan, & Zimmerman, 1990).

Historically, pain was viewed as a biomedical phenomenon only. Pain involved the sensory processes of nociception and the transmission of nerve stimuli to the brain, where nociception acts independently of the conscious pain experience (McDowell, 2006). Pain was a linear process leading from the physical pathology to stimulation of the nociceptor, which in turn manifests itself in pain (Asmundson & Wright, 2004). Psychodynamic models of pain then evolved and were among the first to explore the role of psychological factors in pain (Ibid.). Melzack and Wall’s gate control theory of pain in the 1960s was the first to integrate the physical with the sociological components of pain and has since evolved into the neuromatrix model. This newer model integrates learned responses to pain and the influence of social and environmental conditions (Ibid.). From a contemporary biopsychosocial framework, pain is interpreted as the interaction among physical, psychological and social factors, influencing the biology, the perception and behavioural responses to pain respectively. The biopsychosocial approach to pain presents a much broader, multidimensional and complex construct (Asmundson & Wright, 2004).

The measurement of pain is “essential for the evaluation of methods to control pain” (Melzack, 1975). According to Bellamy (1989), pain is the most important symptom of most rheumatic diseases, particularly early on in the disease (Carr et al., 2003), but also the most difficult to measure. Although pain is the main reason why patients with arthritis seek medical attention (Anderson, 2001), pain is inconsistently quantified and recorded as part of usual medical care (Sokka, 2003). Due to its subjective nature, third party quantification of pain is virtually impossible. Early quantitative measures of pain were based on individual responses to physiological stimuli (Sokka, 2003). These have since evolved into measures of pain including the five-point Likert-type scale using descriptors of pain, the 10 cm long visual analogue scale (VAS) with or without anchoring descriptors, behavioral observation and pain faces scales (faces depicting various degree of pain intensity) (Bellamy, 1989). The numerical rating scale appears to be more reliable in illiterate persons than the verbal rating scale (Ferraz et al., 1990), while the VAS is frequently a component of composite scales used in rheumatology, such as the HAQ (Fries et al., 1980). In contrast, the AIMS measure (Meenan et al., 1980) includes four questions related to pain experience, including frequency, intensity, duration of morning stiffness and multiple joint pain. The NHP (Wiklund, 1990) also includes eight questions on pain, with yes/no response options. The length and complicated scoring system of the NHP, as well as its floor effect makes this instrument less popular.

Perhaps the most well-known and comprehensive pain questionnaire is the McGill Pain Questionnaire (MPQ), a generic measure consisting mainly of lists of terms

to describe the quality and intensity of pain (Bowling, 1997; Melzack, 1975). The descriptors used in the MPQ were generated by a combination of literature review, medical experts and patients. The questionnaire, completed by a clinician/researcher in five to 15 minutes, addresses three distinct dimensions of pain: sensory, affective and evaluative. While its reliability appears weak to moderately good (Bowling, 1997), the MPQ is used more frequently for chronic pain than for acute. Bellamy (1989) states that the length and complexity of this tool limit its clinical applicability. A second shorter form of the MPQ (SF-MPQ) has also been developed (Melzack, 1987). That being said, Anderson (2001) criticizes the use of such generic pain measures as the AIMS and MPQ because they are incapable of capturing the fluctuating and recurrent nature of chronic pain related to RA.

RA specific measures of pain include the Pain Articular Index Diagram and the Pain Articular Index List (Stucki, Stucki, Bruhlmann, & Michel, 1995; Stucki, Stucki, Bruhlmann, Maus, & Michel, 1995). These two measures are based on self-report, the former on a mannequin diagram representing 42 joints, and the latter on a list of 16 joints. Both have demonstrated adequate reliability and validity. Anderson (2001) developed the Rheumatoid Arthritis Pain Scale (RAPS) responding to the need for a pain scale that could reflect the pain unique to persons with RA. The scale, developed with individuals with RA, identified commonalities among pain dimensions. Informed by the gate control and the two-stage affective motivational theories of pain, scale items were developed with persons with RA via clinical assessments and interviews. This resulted in

an instrument with four subscales: physiologic, affective, sensory-discriminative and cognitive (Anderson, 2001).

Although the assessment and subjective quantification of pain is part of the ACR recommended guidelines (2002), compartmentalizing pain into one measure fails to explain the impact it has on each location on the body, its intensity, frequency or effect on activity and participation (Lichtenstein et al., 1998). Furthermore, quantifying pain runs the risk of decontextualizing pain from its reality and the impact on a person's various activities and participation. Another point to consider is that less than 10% of variation in pain scores can be explained by variation in radiographic scores or lab tests (Sokka, 2003). Without a patient's input, this approach can arguably be regarded as inadequate to understand and measure the multiple dimensions of pain.

Pain is also an impairment, impacting a person's emotions mood, activity and participation (Lichtenstein et al., 1998). So when you consider the complexity and impact of personal and environmental factors on the experience of pain, the more relevant explanatory model is the biopsychosocial model (World Health Organization, 2001). From this perspective, the experience of pain is mediated by contextual factors. Personal and environmental factors may influence pain perception and the behavioral response to pain. To date, we do not have a comprehensive pain instrument that can localize and quantify pain as a means of monitoring clinical disease activity and individual response to treatment, and differentiate hindering and facilitating factors in coping and managing with pain. According to Bury (1991, p. 451), the "emphasis on

difficulties and disadvantages has been at the expense of studying the responses and positive actions of those affected". All of the pain scales reviewed and listed in Appendix 2 only consider the intensity of pain while taking no notice of any positive aspects of coping with the pain.

Measures of Activity and Participation

Measures have also evolved to examine activity and participation, where, activity refers to the execution of a task or action by an individual whereas participation refers to a person's involvement in a life situation (Badley, 2008; World Health Organization, 2001). Functional ability from a medical rehabilitation perspective is the dynamic between a person's physical and psychological status and the surrounding environment. Assessment of an individual's functional status includes activities of daily living (ADL) or self-care (such as dressing); instrumental activities of daily living (IADL) (such as meal preparation); and mobility (walking). Evaluation in these areas considers the degree of independence in performance of an activity; speed of performance; endurance and/or tolerance; degree of pain during performance; quality of performance; and safety. Jette (1987) has suggested three distinct methods to assess functional status: direct observation, indirect methods, and self-reports. Self-report and performance-based measures of functional status are highly correlated, but may vary with race and sociodemographics (Spencer et al., 2008). Self-reported measures of activity and participation are easy, fast and inexpensive but are subject to cultural interpretation, motivation and readability (literacy) (Pincus & Sokka, 2003). No activity

and participation tool has yet been identified as the “gold standard” regarding the number or range of activities (Pearson, 2000).

There is a plethora of activity and participation tools, both generic as well as RA specific. In the 1960s, the Katz Index of ADL (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963) and the Barthel Index (Mahoney & Barthel, 1965) became the hallmark of functional status assessment tools and commonly served as “gold standards” for validating subsequent assessment tools. These two generic tools, along with the Lawton IADL scale (Lawton & Brody, 1969) evaluated ADL and mobility as assessed by a health care expert. The generic Index of Social Functioning (Chambers, Sackett, Goldsmith, Macpherson, & McAuley, 1976) and the Sickness Impact Profile (SIP) (Bergner et al., 1976) both published in the 1970s, and the Older Americans’ Resources and Services Multidimensional Functional Assessment Questionnaire (OARS) (Fillenbaum & Smyer, 1981) are completed by a health care provider. These tools are primarily based on observation of an individual’s capacity to execute an activity, potentially discounting what the individual would actually do in terms of performance in their own environment.

In the 1980s, a new wave of activity and participation outcome measures emerged, laying greater emphasis on a client’s self-report, thereby facilitating insight into the impact of the environment on a person’s actual performance. Arthritis-specific measures include the AIMS and the AIMS 2 (Meenan et al., 1980; Meenan et al., 1992), which use self-report to measure mobility, ADL, IADL, pain and mood; the AIMS2 added

elements of work and social supports. RA-specific tools include the Functional Status Index (Jette, 1980) and the HAQ (Fries et al., 1980) and its derivatives: the HAQ-Disability Index (Fries et al., 1982), the modified HAQ (Pincus, Summey, Soraci, Wallston, & Hummon, 1983) and later the Multidimensional HAQ (Pincus, Swearingen, & Wolfe, 1999). More recently the Recent-Onset Arthritis Disability Index (ROAD) (Salaffi et al., 2005), the Measure of Activity Limitation (MAL) (Goodacre, Smith, Meddis, & Goodacre, 2007), (Goodacre, Smith, Meddis, & Goodacre, 2007), the World Health Organization Disability Assessment Scale II (WHODASII) (Üstün, Kostanjsek, Chatterji & Rehm, 2010) and the Valued Life Activity (VLA) Scale (Katz, Morris & Yelin, 2006) were made available. Unique amongst the tools is the McMaster Toronto Arthritis (MACTAR) Patient Preference Disability Questionnaire (Tugwell et al., 1987). This tool acknowledges the individual value and priority given to different functional activities. However, it can be complex to use and requires trained interviewers, limiting its feasibility for clinical settings (Verhoeven, Boers, & van der Liden, 2000). The International Classification of Functioning core set for RA (Stucki et al., 2004) is another complex coding tool with limited clinical applicability, but is informed by the biopsychosocial framework and considers all the contextual factors implicit in a person's activity and participation. Alternatively, the VAL Scale emphasizes the range of obligatory to discretionary activities that individuals may need to modify as a result of RA (Katz, Morris & Yelin, 2006).

Given the relevance of the MHAQ in this study, it is worth noting the proven validity and relevance of the MHAQ and its precursor, the full HAQ. The complete HAQ

has demonstrated high criterion validity when compared to physical capacity measures or observed performance of activity; good correlations with both clinical and laboratory measures; and high test-retest reliability (Bruce & Fries, 2003; Fries et al., 1980; Maska et al., 2011). Construct validity of the full HAQ has been confirmed by factor analysis and sensitivity to change is high. The MHAQ also has high test-retest reliability and correlates highly with the full HAQ (Pincus et al., 1983) as well as clinical changes (Ziebland, Fitzpatrick, Jenkinson, Mowat, & Mowat, 1992). Construct validity has not been demonstrated in the MHAQ by differential item functioning due to the one-dimensional nature of the eight-item questionnaire. However, it is possible that the short form differentiates between upper and lower limb function (Maska et al., 2011). The MHAQ appears to have better predictive validity for five-year mortality than radiographic and laboratory measures. The most significant weaknesses of the MHAQ are potential floor and ceiling effects (Pincus et al., 1983; White et al., 2011); lack of sensitivity to change (Stucki et al., 1995; Wolfe, 2001); and the sole focus on self-care activities at the expense of productivity and leisure activities (Ripat, Etcheverry, Cooper, & Tate, 2001). The full HAQ has also been criticized for only accounting for two types of accommodation, that is, devices and assistance, but not limitations or taking more time, the latter which has proven to be more common among obligatory activities (Katz & Morris, 2007). The MHAQ commonly incorporates a Visual Analogue Scale (VAS) for pain, which itself has moderate to high test-retest reliability (Ferraz et al., 1990; Rohekar & Pope, 2009) and sensitivity to change over time (Hawker, Mian, Kendzerska, & French, 2011). Reliability tends to lessen when used with individuals with low literacy

(Huskisson, 1974). A VAS used to measure fatigue also has moderate to high reliability (Rohekar & Pope, 2009).

The majority of these outcome measures have been informed by a biomedical approach. The notion of “normality” and deviation from a “normal” state, as commonly judged in such functional status assessment measures, is criticized by disability rights advocates as representing persons with disabilities as lacking capacity and requiring care (Bickenbach et al., 1999). As well, the medicalized approach taken by medical rehabilitation to social issues faced by persons with disabilities has been criticized as irrelevant and inappropriate (Finkelstein, 1989). The over-emphasis on the normalization of functional status does not address the issues of a society made inaccessible by attitudes and physical barriers. For disability advocates, disability represents the oppressive relationship between people with impairments and disabling societies where laws and policies are needed to remove those barriers that exclude individuals (Shakespeare, 2005a).

According to Bowling (1997), a major problem facing the measurement of disability is that different people may act and perform tasks differently with apparently similar impairments. The difference in execution will depend on personal expectations, priorities, goals, social support networks, the built environment, technical aids and adaptations. Many of the outcome measures at this time are not sensitive enough to capture the nuances and breadth of activity and participation. A social disablement framework recognizes the individual and social circumstances impacting activity and

participation and demands a sensitive and responsive means of addressing limitations and restrictions. In contrast, critics of the social model of disability cite the denial of the impact of the impairment on disability as a fundamental flaw of this model (Thomas, 2004). If addressing activity and participation in the community means environmental adaptation as well as medical intervention of the impairment, then an integrative model of the individual biomedical and sociopolitical approaches is required (Williams, 1987). If traditional medical approaches to the assessment of the activities an individual can perform are limited in their scope by ignoring the social significance, then their utility is thereby limited. This recognition demands reflective inquiry of clinicians as to the social forces and moral values that underlie their own perspective and the capacity and performance of their clients (Ibid.). Instead, greater emphasis should be placed on what the individual *can* perform and what facilitators are required to enhance their participation in expected societal roles within their family and broader community. According to Katz & Morris (2007), the broad range of possible accommodations must be considered when estimating the total disease burden. Although many authors recommend the HAQ or one of its derivatives, none of the activity and participation assessment tools listed appear to address these concepts, other than the Valued Life Activity (VLA) Scale (Katz, Morris & Yelin, 2006).

Existing disability measures have been extensively tested for validity (whether or not the measure is truly measuring what it purports to measure) and reliability (whether or not a measure yields consistent answers) and have been proven to provide a methodologically trustworthy source of data (Bellamy, 1989; Bruce & Fries, 2003;

Fitzpatrick, Ziebland, Jenkinson, Mowat, & Mowat, 1993; Gignac, Cao, McAlpine, & Badley, 2011; Hakala, Nieminen, & Manelius, 1994; Hernandez-Cruz & Cardiel, 1998; Lillegraven & Kvien, 2007; Pincus & Sokka, 2003). In contrast, the significant weakness of disability measures is the extraction of singular activities out of an individual's personal and social context, thereby risking the omission of activities which may be more meaningful and relevant to the individual (Carr & Thompson, 1994; Goodacre et al., 2007; Kaufert, 1983; Ripat, Etcheverry, Cooper, & Tate, 2001). The risk in using any quantifiable measurement tool is the possibility of limiting the information gathered to the items listed in the tool. While this has the distinct advantage of standardization, when the measure is too short or captures too few domains, it loses its sensitivity. Yet if the tool is too long, it takes too much time and is no longer clinically feasible. The result is the potential incongruity between the health care provider's perspective of activity limitations and participation restrictions and the perceived reality of the client/patient.

Evidence shows that patients' opinions about their status or outcome do not necessarily coincide with their health care provider (Hewlett, 2003; Hidding et al., 1994; Kivela, 1984; Marshall & Murphy, 2008; Slevin, Plant, Lynch, Drinkwater, & Gregory, 1988). Several investigations have assessed the relationship between self-assessment of disability in individuals with RA and that assessed by a physician or health professional. Kwoh and colleagues (1992) reported the degree of agreement between clinicians' assessment and 166 individuals' self-assessment of physical and mental capacity and performance was only 0.39 and 0.30 respectively. This disagreement differed in magnitude and direction depending on the level of disability. Carter and associates

(2007) found in their study of 223 persons with RA that rheumatologists significantly overestimated the degree of disability using the Health Assessment Questionnaire (HAQ) - Disability Index. When used with the Tlingit Indian population of Southeast Alaska, MHAQ scores significantly underestimated disability when compared to physician assessment (Ferucci et al., 2004). According to Hewlett (2003), discrepancies in scores may occur in part because patients are measuring their illness while professionals rate the disease.

Global Measures

Global assessment of disease activity is another common method of evaluating the overall impact that RA has on an individual at a given point of time (Anderson, Zimmerman, Caplan, & Michaud, 2011; Rohekar & Pope, 2009). These assessments are completed either through self-report or by the health care provider. The measure is typically a 10-cm line, with anchoring descriptors at either end. Of the measures listed only the AIMS and the HAQ are specific to individuals with RA; all others are used across various conditions. The HAQ and the AIMS have become frequent health status instruments of choice by clinicians and researchers working with persons diagnosed with RA (Fransen & Stucki, 1998), and are often considered the gold standard by which to compare new instruments.

In the RA population, Patient and Physician Global Assessments (PGA and MDGA respectively) are typically used in conjunction with the MHAQ to assess the general impression of disease activity. They are both reliable tools, but the MDGA more so than

the PGA (Hernandez-Cruz & Cardiel, 1998; Rohekar & Pope, 2009; Uhlig, Kvien, & Pincus, 2009). The correlation between the two is poor (Uhlig et al., 2009). This is explained by the fact that the two respondents may be assessing different constructs as mentioned earlier; that is, patients are measuring their illness while professionals rate the disease (Hewlett, 2003). While the physician's assessment may take into account radiographic and lab results, the patient may be assessing priorities, experiences, expectations, attitudes, and quality of life (Anderson et al., 2011).

Cross-cultural Adaptation of Outcome Measures

High reliability and validity coefficients in-and-of-themselves do not necessarily indicate that a scale is meaningful or relevant to those completing the tool (Aday & Cornelius, 2006). Statistical methods may be limited by assumptions about the differences or variances within and between groups of individuals, such as when using similar measures cross-culturally (Angel, 2006). Self-report and performance-based measures of disability for example, are highly correlated, but may vary with race and sociodemographics (Spencer et al., 2008). Cross-cultural studies attempt to understand how persons from different cultures perceive their situations within his/her own cultural context (Lopez, Figueroa, Connor, & Maliski, 2008). Cross-cultural validation of instruments used to assess health status, activity and participation typically focus on international comparisons instead of ethnic diversity within a country (Ren & Amick, 1998). By not considering the diverse perspectives where such variables as language and beliefs around disease, pain and wellness may diverge widely, false assumptions

clinically and in research are possible, leading to erroneous results and irrelevant interventions. When measures are merely translated into another language from English, measurement error can arise from inadequate translation, inappropriate content, and insensitivity of items, resulting in the loss of conceptual equivalence (Hunt & Bhopal, 2004; Squires, 2009).

One solution is to develop a new and culturally appropriate instrument that can address levels of literacy, taboo subjects such as stigma, and social desirability specific to a particular cultural group. The drawback is the inability to make cross-cultural comparisons. Alternatively, one can translate and adapt a previously developed and validated instrument that already exists (Hunt et al., 1991; Ren & Amick, 1998), referred to as cross-cultural adaptation (Guillemin et al., 1993; Harkness, Pennell, & Schoua-Glusberg, 2004; Hunt et al., 1991). Adaptation not only requires knowledge of the language, but also of the local cultural interpretation and practices (Zinke, Lam, Harden, & Fogg, 2010).

Ware and colleagues (Ware et al., 1995) suggest the following three-step process to adapt health status instruments from one language and culture to another.

1. **Reproduction of the instrument:** The instrument or questionnaire is translated, back translated, and undergoes a cross-cultural comparison for face validity; that is, the extent that the content appears to measure the variable under measure (Bowling, 1997). Quantitative and qualitative methods maximize the conceptual equivalence of both item and scale scores.

2. Reproduction of the scoring algorithms: Psychometric methods are used to test whether items can be combined into multi-item scales that satisfy scaling assumptions and achieve comparable scores across distinct cultural groups.
3. Reproduction of interpretations: Structural models can be used to study relationships that form the theoretical basis of interpretation. Factor analysis can be utilized to explore summary measures. Data can also be interpreted in relation to national and/or international norms where available.

While translation and back-translation is important, there is no set of standards or procedures for translating questionnaires or assessing their quality (Harkness et al., 2004). As a result, it is important to use statistical analyses and modeling to assess the performance of measures, along with qualitative validation. The different quantitative methods used for testing cross-cultural adaptation of instruments include correlation testing (e.g., with Pearson's r), latent variable modeling, and confirmatory factor analysis to test for cultural differences in responses between groups. Latent variable models such as a factor analysis are crucial to the validation of measures used to compare groups in order to ensure fairness and equity (Meredith & Teresi, 2006). Different results between scales require determination of whether the differences are due to translation problems or a difference in health status between population groups. Differences must be explored as true group differences or a product of group-specific attributes that are unrelated to the construct of interest (Gregorich, 2006). For example,

race and ethnicity may act as proxy variables for quality of education, wealth, and perceived racism, and when accounted for separately, effects of race/ethnicity are lessened (Manly, 2006). That is, group differences may be due to education and socioeconomic status, not ethnicity per se.

While quantitative analyses can determine procedural equivalence, interpretive equivalence can best be met with qualitative methods to ascertain cultural differences in meaning (Johnson, 2006; Krause, 2006). Qualitative methods have been found to be of particular value to cross-cultural and disability research (Harkness et al., 2004; Jamieson, Parker, & Richards, 2008; Kroll, Barbour, & Harris, 2007; Richmond & Ross, 2008; Strickland, 1999a). Methodological diversity, each with its own cultural bias, lessens the likelihood of relying on any one set of assumptions (Moghaddam, Walker, & Harré, 2003). In terms of the validation of methodology, recommendations to maximize the trustworthiness of translated data include the consideration of translator credentials; translator role; conceptual equivalence; and details of the methodology itself (such as pilot testing of translated interview guides and recognition of the impact of the use of translators) (Squires, 2009). Alternative interpretations resulting in under- or over-estimated scores can have far-reaching implications, including access to specialty care and services that may hinge on the extent of the disability measured.

In rheumatology, some tools currently in use have been translated for linguistic and cultural relevance using the processes discussed above (El Meidany, El Gaafary, & Ahmed, 2003; Escalante et al., 1996; Gonzalez, Stewart, Ritter, & Lorig, 1995;

Kucukdeveci, Sahin, Ataman, Griffiths, & Tennant, 2004; Neville, Whalley, McKenna, Le Comte, & Fortin, 2001; Osiri et al., 2009; Tammaru, Strompl, Maimets, & Hanson, 2004; Zinke et al., 2010). The Spanish version of the MHAQ was assessed for language equivalence; test-retest reliability using Intraclass Correlation Coefficients (ICC); construct validity by comparing results with an occupational therapist's performance evaluation; and concurrent validity by comparing results with the Steinbrocker functional class, which considers the impact of RA on occupation (Escalante et al., 1996). An Arabic version of the HAQ was assessed for internal consistency, reliability and construct validity by comparing the results with other existing disease activity measures (El Meidany et al., 2003). The Thai version of the HAQ was tested by Cronbach's alpha for internal consistency; the ICC for test-retest reliability; Spearman's correlation coefficients for construct validity; and score means for test sensitivity over three months (Osiri et al., 2009). All studies demonstrated that their adaptations were as reliable and valid as the original instrument.

Adaptation or evaluation of any health outcome measure commonly used in rheumatology for use with an Indigenous population has been virtually non-existent in the peer-reviewed literature. An exception was the publication by Jimenez and colleagues on the experience of pain in North American Native (NAN) peoples, its epidemiology, assessment, management, and its relationship to health care utilization (Jimenez, Garrouette, Kundu, Morales, & Buchwald, 2011). Their systematic review concluded that NAN peoples had difficulty in reducing the experience of pain to a number or abstract score. Kramer, Harker and Wong (2002) have suggested that

American Indians may underreport symptoms of joint pain, a construct typically measured in the HAQ and MHAQ. In a recent qualitative study exploring the communication of pain in two rural Australian Aborigine communities, under-reporting of physical pain was associated with previous negative health care encounters, discrimination, and communication problems (Strong, Nielsen, Williams, Huggins, & Sussex, 2015).

The merging of ethnicity, culture, and disability within such measures is complex as they are all framed by individually and socially defined values and beliefs. Cross-cultural applicability of the biopsychosocial model is defended as being within the domain of contextual factors in the ICF (Üstün, Chatterji, Bickenbach, Trotter II, & Saxena, 2001) and is supported as an appropriate approach to the Indigenous health experience (Alford, Remedios, Webb, & Ewen, 2013; Beaudin, 2010). Evidence suggests, however, that current Western disablement models cannot adequately describe and explain disability through “linear diagrams that connect rationally defined categories through logical principles” (Iwama, Thomson, & Macdonald, 2009). A non-linear worldview demonstrated by the traditional Medicine Wheel, depicts a state of harmony between the spiritual, physical, emotional and social component of the self and the community (Getty, 2010). While Indigenous worldviews continue to evolve, most are founded on a systems model that recognizes that the ecosystem is adaptive; each system is multi-dimensional; and the whole is more than the sum of its parts (Ibid.). In a worldview emphasizing the collective over the individual, a disability limiting one’s

ability to contribute to social relationships among interdependent families and communities may be of greater concern (Ripat & Woodgate, 2011).

A recent systematic review of the use of the ICF (Figure 1) in Indigenous healthcare resulted in only five articles (Alford, Remedios, Webb, & Ewen, 2013). Only one publication focused on using the ICF to explore Indigenous health and disability (Beaudin, 2010). Paul Beaudin, a speech language pathologist, originally from Manitoba (Canada) and self-identifies as Aboriginal, argued that the dominant biomedical approach does not address the specific needs of Aboriginal Peoples. The ICF on the other hand, can provide an appropriate guiding framework to assist in the identification of culture specific health care policies, programs and services needed to address health inequities in Canada. He suggests that while western cultures may interpret the ICF model from left to right, an Aboriginal approach may view it in reverse, that is, participation is related to activity that is related to body function and structures. Beaudin took the liberty of moving personal factors above the health condition in the model, depicting the influence of personal factors on the very existence of the health condition itself. Within personal factors, the author recognizes the balance of physical, mental, spiritual and emotional wellness of the individual, mediated by the community and the Earth.

In any attempt to depict a disablement process more conducive to a traditional worldview, input into the development and formulation of such a model requires community input from a range of perspectives but specifically from First Nations

persons with a disability. Peschken (2013) cautions however, that homogeneity within ethnic designations should not be assumed, particularly when the goal is individualized patient-centred care for all. There is limited value in trying “to describe ethnic groups objectively in generalizations assumed to apply to all members of the group” (Phinney, 1996).

2.3 Summary

The use of models and theoretical frameworks help organize complex material (Campbell, 2006) and the decision-making process pertaining to resource allocation (Wade & de Jong, 2000). Models help in the analysis and understanding of individual clinical cases as well as provide a framework for service planning, implementation and research (Ibid.). The biomedical model has historically framed individual clinical assessment and treatment and has been invaluable for assessing disease activity and population health trends. The result has facilitated relevant program planning and the rationalization of limited goods and services. The weakness of this model lies in the minimization of complex multidimensional processes such as pain, disablement and the personal and social impact of disease. Both the social disablement model and the biopsychosocial model support the notion that disablement represents a series of related concepts whereby a health condition, such as RA, impacts body functions and structures, individual activities and the wider participation in society (Jette & Keysor, 2003). Where these two models differ is the focus on the abilities (or the inabilities) that

a person has and the role of society in creating mediating effects on function and social participation. These two frameworks have re-shaped the evaluation of QoL, activity and participation into a more meaningful exploration into the personal and social context of disablement.

As well, reducing disability to an individual medical problem or to a socially created form of oppression is insufficient. Disability is the “oppressive relationship between people with impairment and disabling societies” (Shakespeare, 2005a, p. 87). Furthermore, understanding the impact and meaning of disability within a cultural context from multiple perspectives is critical (Armstrong & Fitzgerald, 1996). Exploring relative perspectives of normality, power, capacity, social existence and relevance of the body has merit (Ripat & Woodgate, 2011). To truly understand the relevance and validity of specific outcome measures in a First Nations population with RA, further exploration is required. Outcome measures must reflect meaningful engagement of persons within their determined social roles and broader community. Only then can the unique experience of disability familiar to First Nations persons with RA be addressed.

A call for comprehensive efforts to adapt and validate assessment tools cross-culturally has been made (Harkness et al., 2004). To date, no studies have assessed tools used in rheumatology; that is, by translating and/or validating for linguistic and cultural relevance in Canada’s Indigenous Peoples. Current instruments to measure pain and disability including the MHAQ (Pincus et al., 1983), may provide an incomplete picture of the lived experience of pain, activity and participation in First Nations individuals

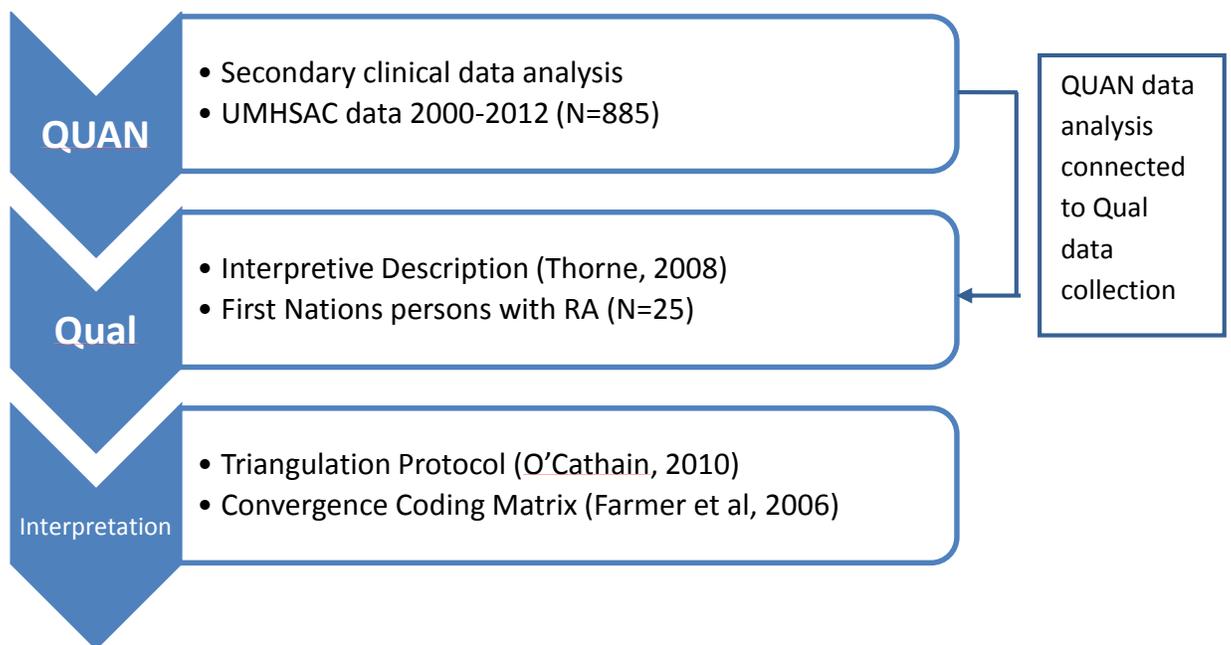
living with RA. A greater understanding of this lived experience is possible through a lens incorporating both quantitative and qualitative perspectives.

3. Materials and Methods

A mixed methods approach was used to assess the appropriateness and relevance of the MHAQ currently in use at the University of Manitoba Health Sciences Arthritis Centre (UMHSAC). Mixed methods research includes combining quantitative with quantitative methods; qualitative with qualitative methods; and more commonly, quantitative with qualitative methods (Williamson, 2005). The latter was selected for this study. According to Creswell (2009, p. 230), mixed methods “involves philosophical assumptions, the use of qualitative and quantitative approaches, and the mixing of both approaches in a study”. Mixed methods have the advantage of “triangulation” or corroboration of different methods (Duffy, 1987). The term “triangulation” comes from the military and navigational strategy of using multiple viewpoints to gain the greatest accuracy; when effectively used between methods, convergent validity⁶ is the outcome (Jick, 1979). Mixed methods can result in complementary or clarification of findings; the development of one method informed by the findings of the other method; initiation of one method based upon the findings of another method; and the expansion of the inquiry (Bryman, 2006; Creswell, Fetters, & Ivankova, 2004; Kroll, Neri, & Miller, 2005). Mixed methods are a promising means of exploring and/or clarifying the context of quantitative findings, particularly in disability research (Kroll et al., 2005). To this end, a sequential explanatory research design was used (Figure 2), whereby the quantitative phase of the study was carried out first, followed by a qualitative phase to explain the quantitative findings (Creswell et al., 2004). Embedded within the qualitative phase was an additional mixed method, whereby a quantitative element was introduced; this is

explained further below. The results of the quantitative data analysis were connected to the data collected in the qualitative phase (Creswell, 2009) and the two phases were linked at the interpretative level after each data set was analyzed using its own methodological analysis (Sandelowski, 2000).

Figure 2. Sequential Explanatory Research Design



To explain this design further, the chapter is divided into five main sections. The first describes the University of Manitoba Health Sciences Arthritis Centre (UMHSAC) database from which the sub-sample was selected for the quantitative study phase. This section describes the available data from which the quantitative analyses can be interpreted. The second section focuses on the statistical methods used in the

quantitative phase, univariate, bivariate and multivariate analyses, and how they were used to address the research questions. The third section focuses on the methods used in the qualitative phase of the study, including interpretive description methodology, sampling and recruitment, and analysis of the semi-structured interviews. The fourth section focuses on the method of interpreting and integrating the two phases, followed by ethical considerations and a summary.

3.1 UMHSAC Longitudinal database

The quantitative first phase involved secondary analysis of the University of Manitoba Health Sciences Arthritis Centre (UMHSAC) longitudinal clinical and research database. This database holds the clinical records of more than 8000 individuals seen by one of six rheumatologists between 1990 and 2012, in Winnipeg, Manitoba. Available variables in the database include individuals' primary diagnoses; demographic information gleaned from a self-reported questionnaire; self-reported measures of pain, fatigue, satisfaction, activity and participation; serology; treatment; and rheumatological clinical assessment results. The diagnosis of RA is only made if the individual has met the American College of Rheumatology diagnostic criteria (American College of Rheumatology Subcommittee on Rheumatoid Arthritis Guidelines, 2002).

This database has formed the basis of other related research including an existing study entitled "The Early Identification of Rheumatoid Arthritis in Canadian First Nations People", currently being conducted by Dr. Hani El-Gabalawy and his research

team at the University of Manitoba Health Sciences Arthritis Centre (UMHSAC) (Deane & El-Gabalawy, 2014; Smolik, Robinson, Bernstein, & El-Gabalawy, 2013).

Variables of Interest to the Current Study

Of particular interest to this study were the variables of diagnosis, ethnicity and self-reported measures of pain and activity, including individual item and total MHAQ scores. Patient's reported their perceived intensity of pain as well as fatigue and patient-reported global disease activity (PGDA) on visual analogue scales (VASs), using 100 mm lines (Appendix 1). Their ranking of pain was measured manually with a ruler and entered into the database by research staff; a variable of "complete" indicated completion of the MHAQ. Additional data of interest were age, gender, rural or urban residence, time since diagnosis, and self-reported years of education and occupation. Variables including laboratory work (RF, ESR, and CRP), affected joint counts (AJC), Lansbury Index (calculated from AJC), and the physician global VAS (MDGA) were available for comparative analyses.

The clinical dataset included self-reported ethnicity: Asian, Black, First Nations, Métis, Inuit, Hispanic, White, and Other. Prior to November 1999, the term "Aboriginal" was used to represent all Indigenous groups in Manitoba and may have been irregularly interpreted and collected. As of November 1999, individuals were provided with a choice of "First Nations", "Métis" or "Inuit" categories. While the term "White" was

offered as an option of ethnic background, we have opted to use the term “Caucasian” instead.

Database Subset for the Current Study

This quantitative study was restricted to the database population who attended clinical visits from January 2000 to September 2012, at which time “First Nations” ethnicity was collected separately from Métis or Inuit. For this period, the database produced a cohort of 276 individuals who self-identified as First Nations with a primary diagnosis of RA or Juvenile RA (JRA) and 669 Caucasian persons with RA or JRA. Individuals diagnosed with JRA were those diagnosed prior to age 18, assessed and followed elsewhere, and for whom management and care were transferred to the UMHSAC once having reached 18 years of age. Given the clinical nature of the database, the number of clinic visits varied among all individuals, as well as the time interval between visits.

In a sample of the most frequently seen individuals, the 10 most frequently seen persons in the First Nations cohort were seen 27 to 32 times compared to persons in the Caucasian cohort who were seen 34 to 44 times. No significant difference was detected between the first visit MHAQ score and the overall mean MHAQ score using a paired t-test, $t(19) = 0.577$, NS. For consistency and feasibility reasons, we used only data from the first clinical visit after January 2000. This approach was supported by the rheumatologist, Dr. C. Peschken, a member of the PhD committee, and intimately

familiar with the database, as well as a biostatistician with the Biostatistical Consulting Unit of the Department of Community Health Sciences at the University of Manitoba.

Limitations of the UMHSAC Database

A major database limitation is that the database was designed for use in the clinical setting and not for research. With this in mind, we found limitations as follows. There were no linkages to postal codes of principal residence so issues of geography could not be confirmed; treaty status of First Nations persons was not available and therefore the role of Non-Insured Health Benefits could not be explored; intervention(s) were not listed and therefore could not be linked to an outcome; the reliance of respondents on a translator or interpreter was not noted; the impact of medications was not recorded; and the database was no longer being populated thus restricting follow-up studies. Also missing from the database are any values for anti-cyclic citrullinated peptide (anti-CCP) antibody positivity as they were not clinically available at the time of the initiation of the original database in 1990. Moreover, definitions of the terms for ethnic background were not provided to the respondents so a standardized interpretation of the various ethnicity terms cannot be guaranteed.

Of particular relevance was how incomplete data was managed. Where an individual item on the Modified Health Assessment Questionnaire (MHAQ) was left incomplete, the score was entered as "0" into the database, leaving it indistinguishable

from a true score of “0” (no difficulty with an item). This coding weakness is a reflection of the clinical nature of the database and the practice at that time.

Notwithstanding these issues, the advantage of this database was its accessibility and that the MHAQ, which was captured within, was still used clinically.

3.2 Quantitative Methods

Quantitative Sample Selection

For this study, the population of interest was the First Nations adults diagnosed with Rheumatoid Arthritis (RA) or Juvenile Rheumatoid Arthritis (JRA) at the University of Manitoba Health Sciences Arthritis Centre between January 2000 and September 2012. Exclusion criteria were a missing MHAQ. Inclusion criteria were being over the age of 18; a confirmed diagnosis of RA or JRA; self-identification as First Nations; and a complete MHAQ. This resulted in a cohort of 252 individuals. For comparative purposes, a cohort of Caucasian adults with RA or JRA for the same timeframe was selected using the same criteria, resulting in a cohort of 633 individuals. The overall study sample was therefore 885 individuals.

Selection and Preparation of Variables for Current Study

Variables selected from the database are as follows.

1. Demographic, represented by self-reported ethnicity, gender, number of others living at home, marital status, urban or rural residence, number of years of schooling, disease duration, age at first visit as of January 2000, and employment.
2. Self-reported measures of impairment, activity and participation included MHAQ, morning stiffness (in hours and minutes), satisfaction, pain VAS, disease activity VAS (PGDA) and fatigue VAS. The “completion” variable indicating a complete MHAQ was also selected to ensure the inclusion criteria was met.
3. Serology, represented by rheumatoid factor (RF titer, IU/ml), ESR (mm/h) and CRP (mg/L). Laboratory results were interpreted with caution due to laboratory and staff changeovers over the 12 years of the database timeframe.
4. Rheumatologist assessment, included tender, swollen and affected joint counts, Lansbury Index, and global disease activity VAS (MDGDA). While staffing changes did occur, rheumatology assessment protocols are standardized and proven to be reliable.

Access to and analysis of these variables allowed investigation into the following research questions:

1. What were the completion rates of the MHAQ in individuals with RA who self-identified as First Nations?
2. Was there a pattern in missing responses in the incomplete MHAQs?

3. Where there was complete information, how did the MHAQ scores correlate with other measures of disease activity in persons with RA who specifically self-identified as First Nations?

Study Database Preparation, Variable Recoding and Data Integrity

The data abstracted from the clinical Access database was first converted into Excel. The data was filtered for a diagnosis of RA, JRA and for ethnicity (Caucasian and First Nations only). Age at the time of the first visit as of January 2000 was calculated in Excel from the date of birth and the date of first visit. The data was then uploaded into SPSS statistical software, version 22.0 (©SPSS Inc., Chicago, IL, USA), which was used for all subsequent analyses.

Age at the time of the first visit as of January 2000 was re-coded in SPSS from age in years to four age categories approximating the categories used in the Canadian Community Health Survey 2005-2006 (Sarkar, Lix, Bruce & Young, 2010): under 25; 25-35; 36-50; and over 50 years of age. The duration of the disease was similarly re-coded in SPSS from years to five categories: less than one (1) year; 1-3 years; 4-10 years; more than 10 years; and “unknown”. The years of schooling was re-coded in SPSS from years to six categories based on the school system in Manitoba: 0 years; one to six years (elementary school); seven to nine years (junior high school); ten to twelve years (senior high school); 13-15 years (typical three-year undergraduate degree at universities located in Manitoba); and 16-20 years (postgraduate education). These three

procedures facilitated examination of interaction terms, that is, where one variable may have had an influence on the outcome only when combined with another variable of interest. Further discussion on the use of interaction terms is presented in the section below on bivariate analyses.

Before proceeding with the quantitative methods any further, all data were checked for four aspects of integrity, that is, statistical power, test assumptions, missing data and the characteristics of the MHAQ scale itself. The following are the results of the assessment.

Statistical Power

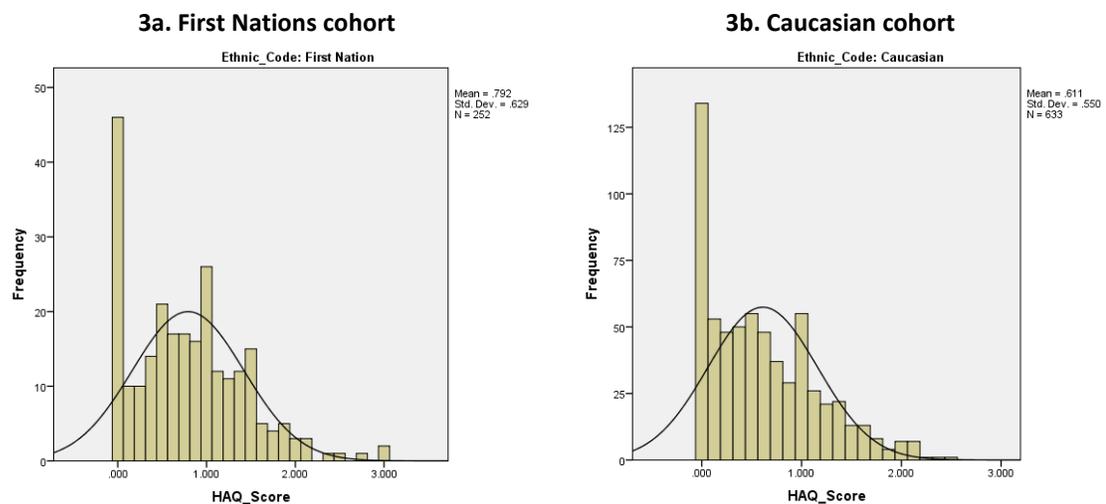
Using G*Power software version 3.1, (Faul, Erdfelder, Lang, & Buchner, 2007), an *a priori* test with a power value of 0.80 (an 80% chance of detecting a true significant difference); an alpha (α) value of 0.05 ($p < 0.05$, that is, the probability that the difference has occurred by chance is less than 5%); and a medium effect size suggested a total sample size of 210 (105 per group) was required for an independent t-test to compare the means of two groups. Applying similar parameters for a linear multiple regression with five predictors required a total sample size of 92. In either case, the sample size in this study far surpassed what is required to glean significant results.

MHAQ Test Assumptions

The MHAQ results for the two cohorts were examined for a normal distribution. The MHAQ scores were not distributed normally, showing a significant positive skewness of the distribution of scores for both cohorts, $p < 0.001$ (Figures 3a & b). Tests

for normality were significant, where both Kolmogorov-Smirnov and Shapiro-Wilk tested as significant, $p < 0.001$. Additional testing of the skewness and kurtosis ratios to standard error, indicated that skewness was significant in MHAQ data for both cohorts but not kurtosis. Collinearity estimates in the multiple linear regression models confirmed that multicollinearity based on the Variance Inflation Factor (VIF) and Tolerance statistic was not an issue. The Durbin-Watson test in the multiple linear regression model of the MHAQ indicated a value of 1.969, supporting the assumption of independent errors. However, the Durbin-Watson value of 0.823 in the multiple linear regression model of the Lansbury Index indicated that residual errors may be correlated and results should be interpreted with caution.

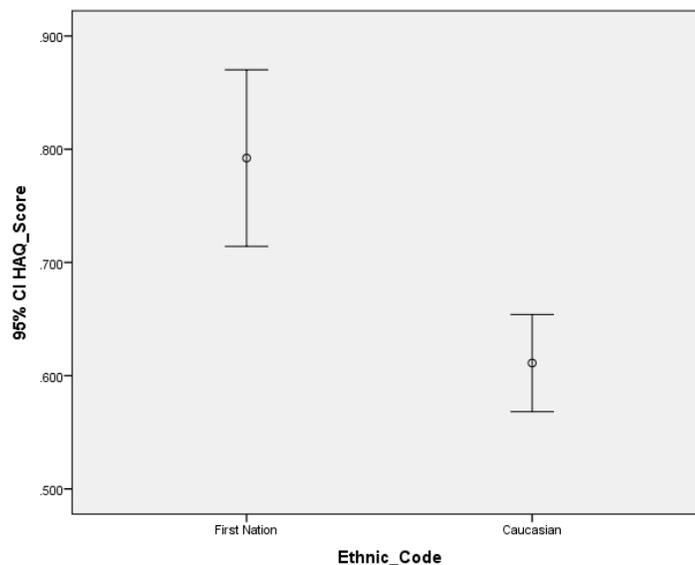
Figures 3 a & b. Histograms of MHAQ Score Distribution



A box plot for both cohorts indicated a significant difference in mean MHAQ scores, with 95% confidence intervals not overlapping (Figure 4). The Levene Statistic test for Homogeneity of Variance, however, tested significant for the mean MHAQ score

between groups ($F= 5.373$ (883), $p<0.05$). Field (2006) recommends a logarithmic transformation of the data where the data is positively skewed. Despite this transformation of the data, a lack of homoscedasticity of the data persisted, suggesting that only nonparametric tests be conducted (Ibid.); a square root transformation had similar results. Given that the data transformation had no significant effect, all subsequent tests were done with the original untransformed data. The equivalent nonparametric Levene Statistic test for Homogeneity of Variance was then conducted comparing the difference in rankings. In contrast, the resulting nonparametric Levene Statistic was $F=2.803$ (883), $p=0.094$, indicating that there was in fact homoscedasticity of the MHAQ score data. Given these contradictory results and the clinical nature of the data, it was decided to conduct both parametric and non-parametric statistical analyses where feasible.

Figure 4. Box Plot of mean MHAQ Scores



Missing Data

Frequency distributions for all variables in the study were undertaken to account for any missing data. The “completion” variable (yes/no response) indicated that 6.3% of the overall database (60 of 945 cases) had missing MHAQ self-reports: 8.7% of the First Nations cohort (24 of 276 cases) and 5.4% of the Caucasian cohort (36 of 669 cases). The key variables of interest - the individual items of the MHAQ responses - were missing, as were all VAS results. These 60 cases were removed from subsequent analyses. This observation alone partially answered the first research question in terms of differences in MHAQ completion between the two cohorts.

It was not always possible, however, to discern missing data from a score of “0” as noted previously in the limitations of the UMHSAC database. On the satisfaction scale of 1 to 4, 4.4% (N=39) of the overall database scored “0” indicating that the scale was not completed; n=22 (8.7%) in the First Nations cohort and n=17 (2.7%) in the Caucasian cohort. There were also many scores entered as “0” on the three VASs: pain, fatigue and disease activity. It is certainly possible that individuals scored themselves as “0” but it is impossible to know for certain whether or not the scale(s) were left unanswered. We noted that a disproportionate number of First Nations individuals had a “0” on the VASs for pain, fatigue and disease activity when compared to their Caucasian counterparts, prompting us to wonder whether the data was actually “not missing at random” (NMAR) (Bannon, 2013). Because this may be true but impossible to verify, these scores were left in the analysis as entered. It was further observed that all individual VAS scores that were entered as “0” for pain were also entered as “0” for fatigue, regardless

of ethnicity. In other words, either both pain and fatigue were truly felt to be non-existent by the respondents, or both scales were left unanswered. Moreover, we found among 100 individuals who were ranked as the most severely affected by their disease by the rheumatologist as measured by MDGA, nine (9) individuals had “0” entered on the pain VAS and fatigue VAS, while 28 individuals had the PGDA (activity VAS) entered as “0”. We assumed that these VASs for pain, fatigue and or activity, representing 3% of the study sample, were left unanswered. Where the rheumatologist assessment data was entered as “0”, the clinical feasibility of no positive findings was confirmed with a clinical expert in the unit, and where possible was verified with a positive entry on another variable. This indicates that the score of “0” in the rheumatologist data is more than likely a true “0” and does not represent missing data. Most missing data was dealt with on a listwise deletion basis for each individual analysis (Bannon, 2013; Bennett, 2001). Where less than 10% of data was missing, all data was left in the analysis (Table 1).

Table 1. Missing or Unknown Data in UMHSAC Database

Variable	First Nations (n=252) Frequency of missing data (%)	Caucasian (n=633) Frequency of missing data (%)	Overall (N=885) Frequency of missing data (%)	Missing data strategy
Demographic				
Gender	0	0	0	n/a
Ethnicity	0	0	0	n/a
Others at home	0	0	0	n/a
Age at first visit	0	0	0	n/a
Marital status	20 (8)	15 (2.4)	35 (4)	<10%: left as is
Rural or urban	74 (29)	129 (20)	203 (23)	Listwise deletion
Years of schooling	45 (18)	47 (7)	92 (10)	Listwise deletion
Employment	38 (15)	22 (3.5)	60 (6.8)	Listwise deletion
Disease duration	24 (9.5)	97 (15)	121 (14)	Listwise deletion
Self-Report				
MHAQ	0	0	0	n/a
morning stiffness	0	0	0	n/a
Ability today "0"	17 (7)	15 (2.4)	32 (3.6%)	<10%: left as is
Satisfaction "0"	22 (9)	17 (3)	39 (4.4)	<10%: left as is
Pain VAS "0"	31 (12)	36 (6)	67 (7.6)	Unlikely but left
PGDA VAS "0"	53 (21)	81 (13)	134 (15)	Unlikely but left
Fatigue VAS "0"	36 (14)	45 (7)	81 (9)	Unlikely but left
Rheumatologist Assessment				
TJC "0"	87 (35)	229 (36)	316 (36)	Feasibility verified: left as is
SJC "0"	84 (33)	229 (36)	313 (35)	Feasibility verified: left as is
AJC "0"	74 (29)	194 (31)	268 (30)	Feasibility verified & cross- referenced with "new Joint Count" variable: left as is
Lansbury "0"	74 (29)	197 (31)	263 (30)	Feasibility verified: left as is
MDGA "0"	0	1 (0.16%)	1 (0.1%)	<10%: left as is
TJC=Tender Joint Count; SJC=Swollen Joint Count; AJC=Affected Joint Count				

Scale Characteristics of the MHAQ

An assessment of the MHAQ scale was performed before proceeding, using the subsets of data described above. Based on Cronbach's alpha coefficient, the eight items of the MHAQ demonstrated a high level of internal consistency ($\alpha = 0.911$ overall). This

was a consistent finding for the First Nations ($\alpha = 0.920$) and Caucasian data cohort ($\alpha = 0.905$), indicating a high degree of reliability of the MHAQ.

Factor analysis was used to assess the dimensionality of the MHAQ of all data combined using principal components method, resulting in a one-factor solution (Appendix 3), using direct oblimin oblique rotation (for related factors) or orthogonal varimax rotation (for independent factors). The first component explained 61.86% of the total variance, while subsequent components explained less than 10% each. The associated correlation matrix showed that none of the correlation coefficients between the eight items were greater than 0.67 and the correlation matrix determinant of 0.011 indicated that multicollinearity is not an issue. The scree plot confirmed a one-factor solution. Similar results were found when repeating the factor analysis with the First Nations cohort and then the Caucasian cohort (results not shown). The Factor Analysis was repeated with the overall data set using the unweighted least squares method, designed to minimize the residuals between the input correlation matrix and the reproduced matrix. The findings were similar indicating a one-factor solution, where the first factor explained 61.86% of the total variance (results not shown). This finding implies that the MHAQ only measures one dimension or one similar domain of function.

Univariate and Bivariate Analyses

Descriptive statistics of the two cohorts based on ethnicity were analyzed and compared for significant differences using unpaired t-tests to compare means of continuous variables and then repeated with Mann Whitney U-tests for ranked data.

The chi-squared test was used to compare proportions of categorical variables, but given the nonparametric nature of the data, tests were repeated with Kendall's Tau-b for ordinal data. Ordinal (or categorical) data are seen in the individual items of the MHAQ measured on a Likert scale of 0 (no difficulty) to 3 (unable to do), whereas the total MHAQ score is an example of scale data.

Criterion validity (the extent that a measure correlates with the "gold standard" measure of the same concept) (Bowling, 1997; Katz, 2011) was tested by examining the relationship between the total MHAQ scores and pain VAS, Affected Joint Count (AJC), MDGA, and Lansbury Index scores (a combination of ordinal and continuous data). This analysis addressed the third research question of how does the MHAQ score correlate with other measures of disease activity in First Nations persons with RA. This was done first by calculating the Pearson's product moment correlation coefficient, while controlling for ethnicity (partial correlation). Given the nonparametric nature of the distribution of the MHAQ scores, the correlation was re-tested for the variables pain and Lansbury index score, two variables of key interest, with the Spearman's rank-order correlation, as well as Kendall's Tau-b.

Possible interactions between a combination of two predictor variables and the outcome variable were determined using a One-Way ANOVA (Analysis of Variance) (General Linear Model). That is, a combined effect may be possible where individually they are not significant. Re-coding continuous data into categorical data such as years of education into category of education allowed for examination of the relationships

between categorical covariate variables and a continuous dependent variable (the MHAQ) (Bannon, 2013).

Multivariate Analyses

In order to ascertain whether or not any individual variable could significantly predict the MHAQ, a multiple linear regression model was conducted. Predictor variables entered into the model were those found to be positively correlated with the MHAQ in the bivariate analyses. Relevant predictor variables were confirmed with a univariate general linear model, as well as any significant interactions between individual predictor variables; first level interactions found to be significant were also considered in the linear regression.

3.3 Qualitative Methods

The second phase explored issues of relevance and construct validity^G of the MHAQ in a Manitoban First Nations population using a qualitative approach. This phase addressed research questions #4 to #6:

4. How was each of the eight individual items of the MHAQ interpreted by individuals from First Nations in terms of their own lived experience?
5. Were all eight individual items in the MHAQ meaningful to First Nations individuals?
6. What were areas of activity not currently captured by the MHAQ, both those that facilitated and hindered participation in the family and community?

All client participants were asked to complete the MHAQ immediately prior to meeting with the researcher; this represents the quantitative element embedded within the qualitative phase. The qualitative data provided in-depth information about the perceptions of those First Nations individuals completing the self-reported MHAQ, such as meaning and relevance of the individual items. The added value of a qualitative approach was that it supported a culturally relevant intervention (Strickland, 1999), and made transparent the perspectives of this group (Jamieson, Parker, & Richards, 2008; Maar et al., 2011; Richmond & Ross, 2008). For instance, narratives of experience and life stories enable a more nuanced understanding of the cultural and geographic processes that shape the way social resources are understood and accessed by Aboriginal peoples (Richmond & Ross, 2008). The major strength of this study phase was

that it permitted an in-depth exploration of individual experiences not captured through the quantitative measurements alone.

The qualitative paradigm used in this study was informed by interpretive description, an applied method designed to integrate disciplinary logic with practice knowledge development for health professionals (Thorne, 2011; Thorne, Oliffe, Oglov, & Gelmon, 2013). Interpretive description “acknowledges the constructed and contextual nature of human experience that at the same time allows for shared realities” (Thorne, Reimer Kirkham, & MacDonald-Emes, 1997). Stemming from a nursing paradigm, interpretive description has the advantage over other qualitative research methods by informing clinical understanding for health care providers by providing a method more responsive to experience-based questions of interest (Thorne, Reimer Kirkham, & O’Flynn-Magee, 2004). Interpretive description allows the researcher “to explore the contradictions and convolutions of human experience and to render a kind of knowledge that informs us more deeply than is possible with a compilation of that which is easier to surface” (Thorne, 2008, p. 124).

Semi-structured interviews of 30-60 minutes duration were used to explore the impact of RA on the lives of First Nations individuals living with RA; on their levels of activity and participation; and on their role within the family and community. Interviews targeted participant perceptions of the MHAQ as a whole, the individual items, and the relevance and meaning of the MHAQ in relation to their experience of living with RA. The question guide, as reported in Appendix 4 also focused on any unanswered

components of the MHAQ or where multiple responses were given. The results were also used to explore the domains of the MHAQ, particularly activity at the individual level and participation at the family and community levels.

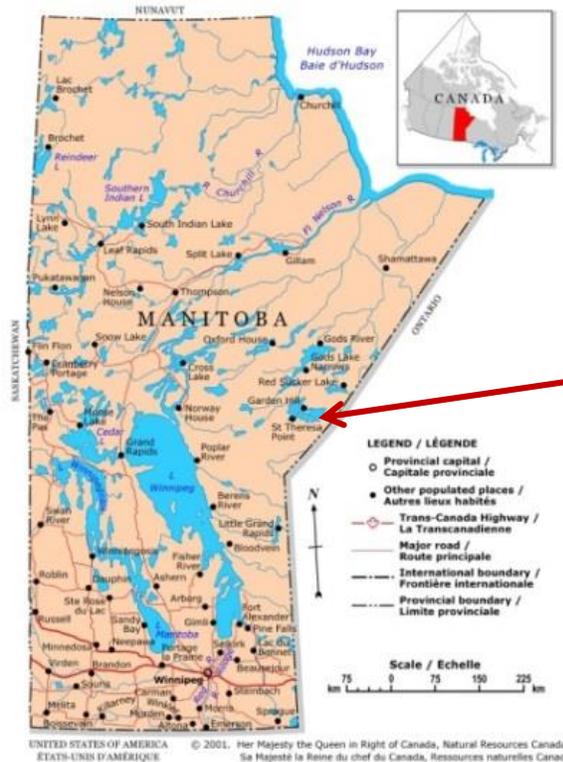
Interviews were audiotaped with the participants' verbal and written consent (Appendix 5) and transcribed verbatim soon after the interview by a trained transcriptionist. This data augmented the researcher's field notes taken during and immediately following the interview. The qualitative data was stored and organized, while maintaining anonymity of all participants by assigning a unique study number. All audio transcripts were erased at the conclusion of the study. Triangulation of methods were utilized to optimize validity and or credibility through the researcher's field notes and reflexivity, verbatim transcripts, and detailed descriptions of the interview. Thorne (2008) advises against the practice of member checking in an interpretive description design because of the risk of over-confidence by the researcher, or alternatively, missed opportunities for a significant result due to the lack of agreement or "derailing" by a single individual. However, individual participants were provided a summary of the findings, either mailed directly to participants or distributed by the research associate according to participant preference. This approach of sharing the results with the participants was deemed consistent with the recommendations of the Tri-Council Policy Statement. The reliability or dependability of the findings was achieved through the variety of methods, as well as code-recode procedures.

Qualitative Sample Selection

Criterion sampling was used to identify persons who self-declared themselves as First Nations with a diagnosis of RA. An additional inclusion criterion was a minimum age of 18. A research associate with the Early Arthritis Study at the UMHSAC helped in the selection process. Potential participants were contacted where possible, prior to their regularly scheduled clinic visit by a research associate to ascertain their willingness to extend their clinic visit to enable the interview; individuals were offered \$25 each for their participation. After the research associate obtained verbal consent, individuals were asked by the researcher to complete the MHAQ on location, the majority of who were waiting to be seen by the rheumatologist. To explore the unique experiences of geographically isolated individuals, the researcher traveled to St. Theresa Point, a First Nation community in the Island Lake Region of Manitoba (Figure 5), along with the itinerant rheumatologist from the UMHSAC in September of 2014. Potential participants were identified first by the rheumatologist and then contacted either by the community research assistant or the research associate to obtain consent (a combination of both theoretical and convenience sampling). Participation in a community radio show to invite potential study participants was also conducted as a means to enhance recruitment. This Oji-Cree community of roughly 3000 residents is situated approximately 610 km northeast of Winnipeg, and is only accessible by plane for the majority of the year, and by ice road in the winter (Community Futures Kitayan, n.d.). Individuals residing in St. Theresa Point could address issues specific to community and environmental adaptation as well as the context of the care delivery model on reserve

in Manitoba. All interviews were conducted in the local nursing station. Translation between English and Oji-Cree was not required by any of the participants. Thirteen interviews were held in St. Theresa Point, at which point no new significant findings appeared to emerge.

Figure 5. Map of Manitoba



(Copied with permission from <http://atlas.gc.ca/site/English/maps/reference/provinceterritories/manitoba>)

Individual interviews were subsequently held between October 2014 and February 2015 with 12 out-patient clients of the rheumatology clinic at the Health Sciences Centre in Winnipeg who self-declared First Nations ethnicity and met the site specific

language inclusion criteria; that is, the ability of the participant to speak English because no language interpreters were available for this study. The rheumatologist and his/her research team identified potential participants who met the language criteria.

To obtain the desired sampling of the most predictable variations of participants (Thorne et al., 1997), emphasis was placed on recruiting a broad spectrum of demographic characteristics, including gender, age and disease duration, while also recruiting a sample of individuals who were representative of the range of individuals in the UMHSAC database used in the first phase of the study. Initial recruitment was based on a combination of convenience and criterion, after which maximum variation was emphasized. That is, potential participants who met the criterion were telephoned in advance to ascertain their willingness to participate. Once in the clinic, their willingness was confirmed. As the qualitative phase continued, special attention was paid to recruit individuals who not only met the criterion, but also who represented gaps in meeting the range of demographics of the database presented in Table 3 (Section 4.1).

Table 2 summarizes the characteristics of the participants who agreed to participate. Overall, the majority of the 25 participants were female (72%), with a mean age of 44 years, mean duration of the disease of 15 years, and a mean MHAQ score of 0.88. Of the Winnipeg HSC cohort, only three lived in Winnipeg. Seven of the participants lived in road-accessible rural communities and three in remote communities accessible only by air. Of interest is the number of people who refused to participate in the study. An additional five individuals were asked to participate in the

Winnipeg cohort; all refused based either on time restrictions or poor winter road conditions (100% female, mean age 58, 80% rural).

Table 2. Characteristics of Participants

Location	Sample size (n)	Female n (%)	Age (years) mean	Disease Duration (years) Mean	Pain VAS (mm) mean	PGA VAS (mm) mean	MHAQ score mean
St. Therese Point	13	9 (69%)	45 ± 11	14 ± 12	52 ± 17	51 ± 18	0.97 ± 0.4
Winnipeg HSC	12	9 (75%)	44 ± 14	16 ± 10	56 ± 21	55 ± 24	0.80 ± 0.5
Overall	25	18 (72%)	44.4 ± 13	15 ± 11	54 ± 19	53 ± 21	0.88 ± 0.5

Interview Settings

All interviews in St. Theresa Point took place in a private administrative room in the nursing station, in a windowless room approximately 10 square feet in size.

Participants sat next to the door, facing the interviewer. Interruptions did occur but were primarily by family members. The interviews in Winnipeg took place at the Health Sciences Centre initially in a clinical examination room, also approximately 10 square feet in size, where the participant sat next to the door, facing the interviewer. After several interviews it became increasingly apparent that the interviews seemed to be overshadowed by the clinical atmosphere. Therefore in order to remove both the participant and the interviewer from the clinical environment, interviews were moved to a non-clinical area two floors away (accessible by elevator) in an unused student

lounge. The room was brightly lit with multiple windows approximately 30 square feet in size. Participants faced the door and the interviewer simultaneously. This change of location perceptively influenced the atmosphere of the interview to one less clinical, free of interruptions, more congenial and relaxed.

Qualitative Analysis

The analysis of the qualitative data was undertaken from two different perspectives: first from the MHAQ itself and secondly from the biopsychosocial model of the ICF (Figure 1). The data was first analyzed using directed content analysis (Hsieh & Shannon, 2005). The goal in directed content analysis is to support (or not support) existing theory, in this case, the measurement of disability as a complex construct as defined by the ICF (WHO, 2001). This lens facilitated the researcher to approach the interview data from the perspective of the respondent in order to develop an understanding of the individual MHAQ questions - the interpretation and relevance to each individual. The qualitative data was then thematically analyzed from the perspective of the ICF, which superimposes contextual issues, culture and relationships upon levels of activity and participation. Constant comparative analysis guided the exploration of such questions as “what is happening here?” and “what am I learning about this?” (Thorne et al., 1997). Constant comparison was used which refers to the initial comparison of data with data, and then the researcher’s interpretations of the data translated into codes and categories or themes (Mills, Bonner, & Francis, 2006).

Strict adherence to constant comparative analysis techniques was not followed as Thorne advises against such a prescriptive approach to data analysis in interpretive description (Thorne, 2008, p. 153). Inductive analysis (beginning with exploration followed by confirmation) (Patton, 2002) and repeated immersion in the data resulted in the development and continuous refinement of coding of categories and themes (Dye, Schatz, Rosenberg, & Coleman, 2000), while looking for patterns within the data and relationships between the data. These relationships were tested by the researcher asking herself, "What ideas are starting to take shape such that I think they will have to have a place in my final analysis if it is to do justice to the research question?" (Thorne, 2008, p. 160). Excel software was used to manage the interview data and organize it by code/theme.

Interpretation of the qualitative data was guided by the following four processes outlined by Morse in Thorne (2008, p. 165-6). The first involved *comprehending*, in which the researcher tried to learn about the impact of RA on the daily lives of the participants. The second was *synthesizing*, where data was merged to describe typical patterns. These were then followed by *theorizing* (the development of explanations) and *recontextualizing* (facilitating application to other contexts). The results from both perspectives are described in detail in Chapter 5.

3.4 Integration of Quantitative and Qualitative Results

The results of the two phases of the study were then integrated using a triangulation protocol suggested by O’Cathain (2010), whereby the results of both phases were used to gain a more complete understanding of the phenomenon under question. After the results were analyzed separately, both the quantitative and qualitative findings were compared for convergence (agreement), complementarity, and discrepancy. The six-steps of the triangulation protocol included the following (Farmer, Robinson, Elliott, & Eyles, 2006): sorting of the data; convergence and or dissonance coding of the data; assessment of the coding results; a completeness comparison; researcher comparison; and feedback to stakeholders. The sorting of the overall data results was completed in light of the goal of connecting the results of the two phases of the study. The quantitative component embedded within the qualitative phase of the study proved to be a particularly valuable method of connecting the findings. The responses in the MHAQ completed by the 25 participants in the qualitative phase of the study were compared with their narratives in a convergence-coding matrix. This matrix was an effective tool to highlight findings in agreement, partial agreement, silence or dissonance (disagreement).

3.5 Ethical considerations

This study built on an existing study entitled “The Early Identification of Rheumatoid Arthritis in Canadian First Nations People”, currently being conducted by Dr. Hani El-Gabalawy and his research team at the University of Manitoba Health Sciences Arthritis Centre (UMHSAC). The University of Manitoba Human Research Ethics Board, as well as the St. Therese Point Band Council, approved that study. Original community and individual consent to the study included consent for on-going analyses such as those described in the first phase of the proposed study. Approval of the quantitative phase of this study was thus a component of the existing agreement with the Auto-Immune Steering Committee, already in place to oversee applications of the longitudinal database held at the UMHSAC. This Steering committee includes representation from the community of St. Theresa Point, MB and other First Nations communities. The principal investigator, Dr. El-Gabalawy, gave written permission for M. Fricke to gain access to the existing database held at the UMHSAC for the purposes of this study (Appendix 6). Explicit approval was also received from the St. Theresa Point Band Council for the portion of this study that took place in the community during phase two (Appendix 7) and the Assembly of Manitoba Chiefs for the population based study (Appendix 8). The principal investigator also received formal approvals from the University of Manitoba Health Human Research Ethics Board (Appendix 9), as well as the Winnipeg Health Sciences Centre (Appendix 10).

3.5 Summary

Relying on multiple and mixed methods in this study helped garner differing perspectives of the utility of the MHAQ in the measurement of disability in First Nations persons with RA. The findings of the various approaches which follow resulted in a thorough exploration and evaluation of the utility of the MHAQ in Manitoba. The findings of the quantitative component of the study follow in the next chapter.

4. Phase 1: Quantitative Findings

This chapter reports on the quantitative analyses, which addressed the third research question pertaining to the correlation of the MHAQ scores with other markers of disease activity. Descriptive results, reported first, are followed by the findings from the bivariate and multivariate analyses.

4.1 Descriptive Analyses

Table 3 shows the characteristics of 885 individuals identified in the clinical database, and are presented by ethnicity cohort. For the period January 2000 to September 2012, no significant differences were found between the First Nations and Caucasian cohorts for gender/sex; living alone; diagnosis; disease duration; or median range of clinic visits. In the First Nations cohort, however, a significantly greater proportion of persons were not married (51% versus 62%); lived with a greater number of people in the same household (up to 10 persons per home versus 8); lived rurally (37% versus 17%); had fewer years of education (8 versus 11 years); were younger at the time of first rheumatology visit (43 versus 53 years of age); and were more likely to list “disabled” as a category of employment (16% versus 10%) ($p < 0.001$). First Nations patients were also more likely to test RF positive ($p < 0.005$).

Table 3. Selected Sociobiological Characteristics, UMHSAC database, January 2000 to September 2012

Characteristic	First Nations (n=252)	Caucasian (n=633)	P value (2-tailed)
Female, % (n)	81 (203)	76 (478)	NS **
Married, % (n)	51 (128)	62 (389)	<0.001 **
Live alone, % (n)	20 (51)	20 (126)	NS **
Others at home, range (median)	0-10 (2)	0-8 (1)	<0.001 *
Live rurally, % (n)	37 (94)	17 (109)	<0.001 **
Education, mean \pm SD (years)	8 \pm 5	11 \pm 4	<0.001 *
Self-reported "Disabled" as employment status, % (n)	16 (40)	10 (66)	<0.001 **
Disease Duration, mean \pm SD (years)	24 \pm 38	23 \pm 35	NS*
First visit age, mean \pm SD (years)	43 \pm 14	53 \pm 17	<0.001*
Diagnosis of RA, % (n)	90 (226)	90 (569)	NS **
Diagnosis of JRA, % (n)	10 (26)	10 (64)	NS **
RF positive, % (n)	46 (116)	36 (226)	<0.005 **
RF titer, mean IU/ml \pm SD	206 \pm 604	102 \pm 276	0.009
# of clinic visits, range (median)	1-32 (9)	1-44 (10)	NS*
# with 1 visit (%)	42 (17%)	130 (21%)	
# with 2-5 visits (%)	46 (18%)	84 (13%)	
# with 6-10 visits	56 (22%)	117 (18%)	
# with \geq 11 visits	108 (43%)	302 (48%)	

* t-test for continuous variables **Chi-squared test for categorical variables

Table 4 shows the differences in disease activity measures of the two cohorts, grouped by lab, self-report and physician assessment (see Appendix 11 for the analyses summarized in this table). Group differences were ascertained using unpaired t-tests, with a two-tailed significance. First Nations had significantly higher disease activity markers as represented by the MHAQ score $t(411) = 4.00, p < 0.001$; Lansbury Index scores $t(395) = 3.74, p < 0.001$; and pain VAS $t(431) = 3.59, p < 0.001$. Tests for significant differences in nonparametric data were repeated using Mann-Whitney U tests. Again, First Nations had higher disease activity as represented by MHAQ scores

($U= 66,640.5$, $p < 0.001$); Lansbury Index scores ($U= 69,392.5$, $p < 0.005$); and pain VAS scores ($U= 67,923.5$, $p < 0.001$) (Appendix 12). There was, however, no difference between the two cohorts for Affected Joint Counts ($U= 75,259$, $p=0.184$) (Appendix 12).

Table 4. Disease Activity Markers, UMHSAC database, January 2000 to September 2012

Type of measure	Variable	Mean (SD)		Difference (95% CI)	P value (2-tailed)
		First Nations (n=252)	Caucasian (n=633)		
Lab	RF titer, IU/ml	206 (604)	102 (276)	104 (26 - 182)	0.01
	ESR mm/h	18 (25)	14 (21)	3.4 (-0.02 - 7)	0.051
	CRP mg/L	11 (18)	11 (22)	.12 (-2.8 - 3)	0.936
Self-report	Pain VAS, 100 mm	50 (31)	42 (29)	8 (3.8 - 12)	0.001
	MHAQ score	0.79 (0.62)	0.6 (0.6)	0.2 (0.09 - 0.26)	0.001
	A.M. stiffness, mins	100 (154)	78 (113)	22 (0.85 - 43)	0.042
	Fatigue VAS, 100 mm	49 (32)	48 (32)	1 (-4 - 6)	0.68
Physician assessment	Lansbury Index	43 (44)	32 (37)	12 (6 - 18)	0.001
	MD Global VAS, 100 mm	20 (21)	16 (19)	3 (.3 - 6)	0.022
	Affected Jt Count	10 (10)	8 (9)	1 (-.2 - 2.8)	0.064

Table 5 shows significant cohort differences on seven MHAQ self-reported activity items, with the exception of the first item, “dress yourself” (see Appendix 13 for analysis of this item). The First Nations cohort reported significantly greater difficulty in rising out of bed, drinking, washing and drying one’s body, reaching, gripping and getting in and out of a vehicle. These differences were maintained when tested nonparametrically using Kendall’s Tau-b. Walking outside on flat ground was also significantly different, with the First Nations cohort reporting more difficulty.

Table 5. MHAQ Activity Items, UMHSAC database, January 2000 to September 2012

At this moment, are you able to...	First Nations (n=252)		Caucasian (n=633)		Chi ² p value	Kendall's Tau-b
	0 - 1*	2-3 **	0 - 1*	2-3 **		
Dress yourself	85% (214)	15% (38)	87% (556)	12% (77)	0.429	0.101
Get in/out of bed	82% (206)	18% (46)	93% (586)	7% (47)	0.001	0.001
Lift a full cup to your mouth	91% (229)	9% (23)	96% (605)	4% (28)	0.001	0.001
Walk outside on flat ground	85% (215)	15% (37)	87% (551)	13% (82)	0.057	0.013
Wash/dry your entire body	81% (205)	19% (47)	87% (553)	13% (80)	0.024	0.019
Bend & pick up clothing from floor	79% (199)	21% (53)	88% (558)	12% (75)	0.001	0.001
Turn faucets on/off	80% (202)	20% (50)	89% (598)	11% (71)	0.005	0.018
Get in/out of car, bus, train or plane	77% (195)	23% (57)	87% (551)	13% (83)	0.001	0.001

* 0 "without ANY difficulty"; 1 "with SOME difficulty;"
 ** 2 "with MUCH difficulty"; 3 "UNABLE to do"

4.2 Bivariate Analyses

The strength of the relationship between the total MHAQ score and other markers of disease activity, while controlling for ethnicity, is presented in Table 6. A moderately strong, positive correlation was detected between the MHAQ and pain VAS ($r=0.574$, $p<0.001$), indicating that as the pain rose, so in turn did the MHAQ score. The pain VAS score explained 33% ($R^2=0.574$) of the MHAQ score, a level described as a medium-sized effect (Bannon, 2013, p.197) (see Appendix 14 for detailed analysis). A weak but positive correlation ($p<0.001$) was detected between the MHAQ and the following: Lansbury Index ($r=0.293$; $r^2=0.086$); affected joint counts ($r=0.285$; $r^2=0.081$); Physician's Global Assessment (MDGA) ($r=0.262$; $r^2=0.0686$); Lab CRP ($r=0.232$; $r^2=0.054$); and Lab ESR ($r=0.227$; $r^2=0.052$). All effect sizes for disease markers were small (Bannon, 2013).

Table 6. Variables positively correlated with MHAQ score

Disease Measure	N	Mean	SD	Min	Max	Correlation Co-efficient
Lab ESR values (mm/h)	885	15	22	0	133	0.227
Lab CRP values (mg/L)	885	11	21	0	153	0.232
Pain VAS (mm)	885	44	29	0	100	0.574
Affected Jt Counts	885	8.7	9.7	0	41	0.285
MDGA (mm)	884	17	19	0	100	0.262
Lansbury Index	885	35	39	0	180	0.293
MHAQ	885	0.66	0.58	0	3.0	1.0

Because a non-normal distribution was detected, the MHAQ scores were re-tested for correlation with pain VAS scores using Spearman's rho as well as Kendall's Tau-b. A significant relationship was confirmed, $r_s = 0.615$, $p = 0.001$ and $T_b = 0.465$, $p = 0.001$ (2-tailed) (Appendix 14). These tests were also repeated for the correlation between MHAQ scores and Lansbury Index scores, $r_s = 0.311$, $p = 0.001$ and $T_b = 0.232$, $p = 0.001$ (2-tailed), and significance was confirmed.

All correlations were maintained regardless of ethnicity, with both cohorts demonstrating similar results. Pain VAS was correlated with the MHAQ score in the First Nations cohort ($r=0.543$, $p<0.001$, $r^2=0.29$) and Caucasian cohort ($r=0.590$, $p<0.001$, $r^2=0.34$), with a medium size effect found in both. The First Nations cohort was positively correlated with Affected Joint Count ($r=0.305$, $p<0.001$, $r^2=0.093$); Lansbury Index ($r=0.266$, $p<0.001$, $r^2=0.071$); and MDGA ($r=0.20$, $p<0.001$, $r^2=0.04$). The Caucasian cohort had similar results with a similar small effect size: Affected Joint Count ($r=0.275$,

$p < 0.001$, $r^2 = 0.075$); Lansbury Index ($r = 0.308$, $p < 0.001$, $r^2 = 0.094$); and MDGA ($r = 0.295$, $p < 0.001$, $r^2 = 0.087$). In other words, no apparent correlated differences between the MHAQ score and other markers of disease activity were found between the cohorts.

The total MHAQ score was then subsequently tested for the strength of its relationship against the following demographic characteristics: 1) gender, ethnicity and living rurally using an independent samples t-test; and 2) age at the time of first visit, education, disease duration using a one-way ANOVA. A significant relationship between MHAQ and ethnicity ($t(412) = 4.002$, $p < 0.001$) was found. Self-identified First Nations persons had a higher MHAQ score (mean = 0.792, SD = 0.63) than Caucasians (mean = 0.611, SD = 0.55), and the Cohen's d at 0.3066 indicated a relatively small effect size for ethnicity on MHAQ score (Bannon, 2013).

When both cohorts were combined and analyzed as a whole using the methods described above, no significant relationship was detected between the MHAQ score and gender, rural background or duration of disease. However, when the cohorts were analyzed separately in order to look for unique features, several differences were apparent. While gender had no discernable relationship to MHAQ score, a rural background was associated with a higher MHAQ score for the First Nations cohort ($t(176) = 2.104$, $p < 0.05$), but not for the Caucasian cohort. Alternatively, disease duration was associated with the MHAQ score for the Caucasian cohort ($F = 3.841$, $p < 0.005$), but not for First Nations.

A significant relationship was also detected between total MHAQ score and education ($F = 12.461$, $p < 0.001$), whereby individuals with fewer years of schooling had

higher MHAQ scores (Table 7). However, after 16 years of education, a slight increase was observed. Education had a medium effect on MHAQ (partial Eta squared effect size=0.066) (Ibid.). For age, a significant relationship was found ($F= 7.124, p<0.001$), where older RA patients had higher MHAQ scores (Table 8), but the effect size was small (0.024) (Ibid.). When assessed between cohorts, only the MHAQ score for the Caucasian cohort, rather than First Nations, remained significantly correlated with education ($F=10.907, p<0.001$) and age ($F=9.608, p<0.001$). The potential for an interaction effect was assessed using a one-way ANOVA, but no significant interaction terms were observed.

Table 7. MHAQ Score by Education

Education Category	N	MHAQ (mean)	SD
0 years (unknown)	92	0.632	0.636
1-6 years	33	0.981	0.627
7-9 years	128	0.958	0.643
10-12 years	401	0.627	0.539
13-15 years	122	0.496	0.489
>16 years	109	0.561	0.520

Table 8. MHAQ Score by Age Group

Age Category	N	MHAQ (mean)	SD
Younger than 25	86	0.398	0.473
25-35 years old	92	0.666	0.571
36-50 years old	248	0.667	0.544
Older than 50	459	0.709	0.604

A similar analysis was undertaken for the Lansbury Index to determine if comparable patterns were observed in an assessment based on medical expertise

versus a patient self-reported function. Like the MHAQ score, there was no significant difference in the Lansbury Index score for gender or rural background, when taken as a whole or by ethnicity. However, a significant relationship was found between the Lansbury Index and ethnicity ($t(395) = 3.744, p < 0.001$), where self-identified First Nations (mean=43.34, SD= 44.23) had higher Lansbury Index scores than their Caucasian counterparts (mean=31.56, SD= 36.67). When tested by a Cohen's d the effect size was small (0.289). The Lansbury Index score was also associated with age ($F=3.148, p < 0.05$) and education ($F=3.882, p < 0.05$) when analyzing both cohorts together. When analyzed separately by cohort, the significant relationship between Lansbury Index and education was found in the Caucasian cohort only ($F=3.004, p < 0.05$).

Unlike the MHAQ score, the Lansbury Index score was associated with disease duration ($F=4.743, p < 0.001$) but the effect size was small (partial Eta squared = 0.021). A significant correlation was maintained by ethnicity ($F^{\text{Caucasian}} = 3.581, p < 0.05$; $F^{\text{First Nations}} = 3.153, p < 0.05$). Interactions were tested and several were observed. The Lansbury Index was significantly associated with age X ethnicity ($F=3.054, p < 0.05$) and age X rural residence ($F=2.226, p < 0.05$). That is, older First Nations individuals and older individuals living in rural communities were associated with higher Lansbury Index scores. The Lansbury Index was also significantly associated with ethnicity x duration ($F=4.602, p < 0.001$), ethnicity x MHAQ ($F=1.798, p < 0.05$), and rural x duration ($F=2.306, p < 0.05$). That is, First Nations individuals with longer disease and higher MHAQ scores had higher Lansbury Index scores as well as individuals coming from rural communities with a longer duration of disease.

4.3 Multivariate Analysis

Linear regression modeling determined whether variables significantly associated with the MHAQ predicted the total MHAQ score. Univariate general linear modeling confirmed that pain ($F=2.365$, $p<0.001$) and MDGA ($F=2.199$, $p<0.005$) were significantly correlated with the total MHAQ score, as were education ($F=12.177$, $p<0.001$), age ($F=6.00$, $p<0.001$), and disease duration ($F=3.256$, $p<0.05$); ethnicity was not significant ($F=0.824$, $p=0.365$). Using these variables as predictor variables of the MHAQ, a hierarchical regression analysis shown in Table 9 found that when pain was entered alone (Model 1), it significantly predicted the total MHAQ score, $F(1, 882) = 449.26$, $p < 0.001$, adjusted $R^2 = 0.337$. As indicated by the R^2 , pain predicted close to 34% of the total MHAQ score, a value representing a large effect size. The standardized co-efficient (Beta-value, β) of pain in Model 1 was 0.581, $p<0.001$. When MDGA was added in Model 2, the model improved the prediction, R^2 change=0.018, $F(1, 881) = 24.586$, $p<0.001$, with pain and MDGA significantly predicting MHAQ ($p<0.001$). Adding the demographic variables of education, age and disease duration into the model, Model 3 improved the prediction, R^2 change=0.016, $F(3, 878) = 7.574$, $p<0.001$. All predictor variables were significant. This third and final model significantly predicted the MHAQ score, $F(5, 878) = 103.892$, $p < 0.001$, with pain, MDGA, education, age and disease duration explaining 37% of the MHAQ score. The standardized co-efficients (Beta-values, β) and significance values (Table 10) show that pain had the highest β -value (0.536), followed by MDGA (0.141), education (-0.077), age (0.076) and disease duration (0.058). From Models 1 to 3, we found a relatively small increase in the R-

value, and a small but significant change in F-value. Regardless, pain was the greatest single predictor of the total MHAQ score. These analyses were repeated with a stepwise regression but no substantial change was observed.

In terms of meeting test assumptions, the Durbin-Watson statistic of 1.956 supported the assumption of independent errors. No evidence of multicollinearity was detected through examination of the Variance Inflation Factor (VIF), Tolerance Score or distribution of the Eigenvalues. The full SPSS output of this analysis can be found in Appendix 15.

Table 9. Hierarchical multiple regression analysis summary predicting MHAQ from pain, MDGA, age, education and disease duration (N=884)

Model	Predictor Variables	R	Adjusted R ²	F Change	Sig F Change
1	pain	0.581	0.337	449.26	0.000
2	pain + MDGA	0.596	0.354	24.59	0.000
3	pain + MDGA + education + age + disease duration	0.610	0.368	7.57	0.000

Table 10. Contribution of individual variables to MHAQ in Model 3 of the hierarchical multiple regression analysis (N=884)

Variable	B*	SEB	B	95% CI for B	P value
Pain	0.011	.001	.536	0.009, 0.012	0.000
MDGA	0.004	.001	.141	0.003, 0.006	0.000
Education	-0.009	.003	-.077	-0.016, -0.003	0.005
Age	7.17 E-6	.000	.076	0.000, 0.000	0.005
Disease duration	0.001	.000	.058	-0.000, 0.002	0.033

* B=Unstandardized Coefficient; SEB=Standard Error of B; β=Standardized Coefficient (Beta); 95%CI=Confidence Interval for B

4.4 Summary

In summary, the First Nations cohort demonstrated significantly higher scores in pain, total MHAQ score, and Lansbury Index score ($p < 0.001$), as well as MDGA and morning stiffness ($p < 0.05$). Significant relationships were observed between ethnicity and the MHAQ ($t(412) = 4.002$, $p < 0.001$) and Lansbury Index scores ($t(395) = 3.744$, $p < 0.001$). The First Nations cohort living with RA had higher MHAQ scores and Lansbury Index scores than the Caucasian cohort. The effect size, however, was small ($d = 0.3066$ and 0.289 respectively). Among the eight individual items of the MHAQ questionnaire, the First Nations cohort scored significantly higher in seven of the eight activities of daily living ($p < 0.05$); only “dressing yourself” was not significantly different between the two groups.

A moderately strong correlation was observed between MHAQ score and pain ($r = 0.574$, $p < 0.001$) and weaker correlations were observed between MHAQ and Lansbury Index, affected joint counts, the physician’s global assessment, and CRP and ESR values ($p < 0.001$). No differences were detected between the two cohorts. There was also a significant relationship detected between total MHAQ score and age ($F = 7.124$, $p < 0.001$), and education ($F = 12.461$, $p < 0.001$), where those individuals older and with less education demonstrated higher MHAQ scores. Similarly, the Lansbury Index score was also associated with age ($F = 3.148$, $p < 0.05$) and education ($F = 3.882$, $p < 0.05$).

When the two cohorts were analyzed separately, significant relationships were detected in the Caucasian cohort only between MHAQ score and education ($F = 10.907$,

$p < 0.001$), age ($F = 9.608, p < 0.001$), and duration of the disease ($F = 3.841, p < 0.005$), and between Lansbury Index and education ($F = 3.004, p < 0.05$). In contrast for the First Nations cohort, rural background was significantly associated with the MHAQ score $t(176) = 2.104, p < 0.05$). Multiple linear regression modeling demonstrated that pain was the single largest predictor of the total MHAQ score.

These quantitative results support the use of the MHAQ in a First Nations population. Criterion and concurrent validity were demonstrated through significant relationships with other established disease markers, while the MHAQ's predictive validity in relation to the Lansbury Index was also supported. The differences noted between the two cohorts, however, required further exploration; these were pursued qualitatively and are described in the next chapter.

5. Phase Two: Qualitative Results

This chapter is a report on the First Nations study participants' understanding of the MHAQ, its value and relevance for Indigenous individuals. The data was analyzed from two different perspectives: first, a directed content approach examining the administration and use of the MHAQ, and second, a thematic analysis guided by the biopsychosocial lens of the ICF (WHO, 2001). The directed content analysis answered the four research questions listed below:

1. What are the completion rates of the MHAQ in individuals with RA who self-identify as First Nations?
2. Was there a pattern in missing responses in the incomplete MHAQs?
4. How was each of the eight individual items of the MHAQ interpreted by individuals from First Nations in terms of their own lived experience?
5. Were all eight individual items in the MHAQ meaningful to First Nations individuals?

In contrast, the thematic analysis answered the following two research questions:

6. What were areas of activity not currently captured by the MHAQ, both those that facilitate and hinder participation in the family and community?
7. How could issues of activity and participation of First Nations persons living with Rheumatoid Arthritis in Manitoba be optimally addressed in the current care model, including both policy and direct service delivery?

5.1 Directed Content Analysis of MHAQ Completion

Replicating the clinical administration of the MHAQ, the MHAQ questionnaire was presented to respondents as seen in Appendix 1. The preamble of the questionnaire instructed respondents to “**Please check off the one best answer** for your abilities at this time”. The MHAQs were completed immediately prior to participants being interviewed. Of the 25 participants, 80% (20) checked off one response per question as instructed. Two individuals ticked off two responses to the same question, and two different individuals left questions unanswered, whereas one individual did both (Figure 6). Of the five individuals who did not complete the MHAQ with one response per question, the mean age was 53 years; three of the five participants were female, and all were from rural Manitoba. These characteristics did not differ from other participants. From this exercise, it was not immediately apparent to the reviewer why participants completed the MHAQ the way they did. Individuals may not have understood the questions in the MHAQ, or they may have been unsure how to account for assistance or daily fluctuations in functional status. Figure 6 illustrates the way in which one individual did not complete the instrument as instructed by answering twice to one question and leaving another response blank.

Figure 6. Example of completed MHAQ

Patient Arthritis Assessment Questionnaire (PAQ)

Name _____ Date _____

The questions below concern your daily activity at this time. Please try to answer each question even if you do not feel it is related to you or any condition you may have. **There are no right or wrong answers.**

1. Please check (✓) the one best answer for your abilities at this time:

At this moment, are you able to :	without ANY difficulty	with SOME difficulty	with MUCH difficulty	UNABLE to do
a. Dress yourself, including tying shoelaces and doing buttons?	0	✓ 1	2	3
b. Get in and out of bed?	0	✓ 1	2	3
c. Lift a full cup or glass to your mouth?	0	✓ 1	2	3
d. Walk outdoors on flat ground?	0	✓ 1	2	3
e. Wash and dry your entire body?	0	✓ 1	✓ 2	3
f. Bend down to pick up clothing from the floor?	0	✓ 1	2	3
g. Turn regular faucets on and off?	0	1	2	3
h. Get in and out of a car, bus, train or airplane?	0	1	✓ 2	3

After this exercise, participants were asked by the researcher to describe why they checked off more than one response or left a response blank. Explanations cited reasons of a lack of clarity in the questions themselves or daily fluctuations in a specific function, which is characteristic of RA. A 67-year old female with a long-standing history of RA explained her multiple responses as follows.

Question (Q): “Lifting a cup or glass to your mouth. You circled ‘0’ and ‘1’?”

Answer (A): “Yes, that's ‘sometimes’. That’s what I asked the nurse over there. What do I do with the questions, you know?”

This response was probed further with a key informant, who described the environment and way patients complete questionnaires in the nursing station of his community.

“It's just like when you're going to a restaurant and they so often... the waiter is bugging you to see how everything - the food-is. That’s how we do it too. ‘Is everything going ok? Are you stumped on something?’ and we come across guys like, if we, it's like... like... uh 5 or 6 or 8 altogether trying to do a questionnaire.”

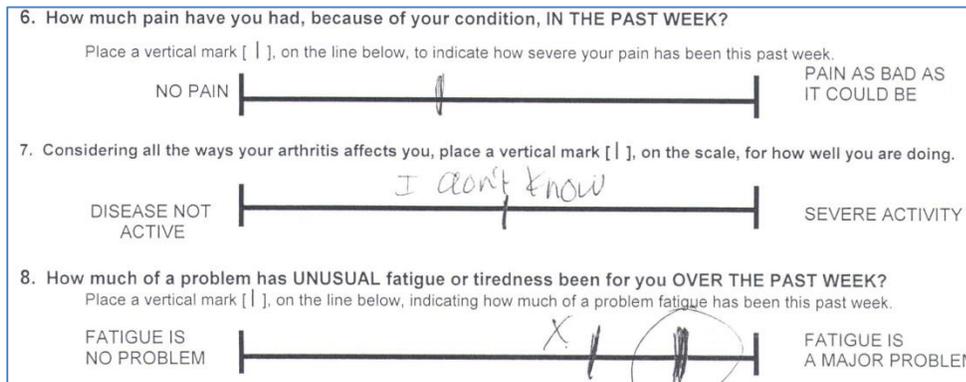
One RA patient, when asked about her confidence in filling out medical forms and questionnaires, replied that she was “very confident” but in our exercise she did leave the first question unanswered. Interestingly, the researcher herself did not notice this omission until after the interview was over. Upon further reflection by the researcher, one reason as to why it was missed may have been due to formatting. The question was placed on the top row in close proximity to the instructions. A lack of spatial differentiation may have contributed to this omission by two participants. Other than the first question left unanswered, no pattern was apparent in missing or incomplete MHAQs.

On the same instrument, Visual Analogue Scales (VASs) for pain, fatigue and disease activity were used, which are common features added to self-reported questionnaires. One individual left them all blank after having completed all the eight individual items of the MHAQ. When asked why, the 34-year old woman who had never encountered the MHAQ before, stated that she “didn’t understand those questions”. While a lack of understanding was voiced, the researcher observed that prior to the interview the participant was outwardly agitated (she had raised her voice in the clinic area) and had completed the questionnaire at a time of emotional stress. Although the participant indicated that she didn’t understand the questions, it was apparent that she had more important concerns than the task at hand. This raises a question of the validity of self-reported questionnaires when administered at a time of emotional volatility and/or stress. It was unclear whether the number of questions or the placement of the VAS questions after the eight MHAQ items and the four additional questions may have

agitated an already agitated respondent, or whether the respondent was too tired or bored to answer them. Another reason for missed data, according to one woman was that it was the language used; she didn't understand the word "fatigue" – a word commonly used to describe the symptoms of RA in the VAS items (as noted).

During the completion of the VAS, three respondents discussed the intensity and nature of their pain on that given day, and following that reflection revised their pain scores; one had scored his response in relation to what he anticipated it would be later that day after he received treatment from the rheumatologist. Another participant, a 23-year old female, marked a line mid-way between "disease not active" and "severe activity" and wrote the comment "I don't know" directly onto the VAS for disease activity. She then revised her response to the VAS fatigue question indicating a high ranking of fatigue is a major problem (as illustrated in Figure 7).

Figure 7. Example of Completed VAS



Completing the VAS as expected was difficult according to a number of respondents. A 56-year old male laborer living in Winnipeg stated, "I don't like those

lines...I really don't understand this way.” While a 54-year old female and former employee of the nursing station explained, “I find it (VAS) difficult. Like, uh, most of the time we use numbers, right?” Both respondents stated they would prefer to provide a numerical response to their pain, such as “on a scale of 1-10, how bad is your pain where 10 is the worst pain you can imagine?” When individual participants were asked this question during the interview, the numerical scale responses given verbally were nearly exactly the same as the measurement of the vertical mark made on the 10 cm line. None of the participants suggested that imaged anchors at either end of the line (e.g. happy/sad faces) would significantly facilitate their responses.

Contextual Relevance of Question Items

While the majority of the 25 respondents responded to each question item, further exploration with participants as to *how* and *why* they replied as they did revealed many more instances of incongruent responses of activities of daily living. Individuals were sometimes unclear as to what context they were being asked to respond when completing the MHAQ. Some individuals interpreted the instruction, “The questions below concern your daily activity at this time,” to mean literally on that day, regardless of whether they were in their home community or not. What this item did not discern is that individuals could perform in one manner at home on a given day in a remote northern community, travel to Winnipeg – a large urban centre the next day for an appointment with a rheumatologist and in that urban environment he/she would act

quite differently. This change in capacity and performance from one day to the next can reflect change in the built environment and the variability of an inflammatory disease. As a 55 year old male on disability assistance who had completed the MHAQ multiple times stated, “It depends on the day...It all depends on what I ... if my arthritis is flaring up.”

Another participant, a 37-year old woman who frequented Winnipeg regularly for her family’s medical reasons, over-estimated her capacity in her home community. She responded “0-without ANY difficulty” in terms of her ability to walking outdoors on flat ground. Yet her ability to walk outside varied between a natural and built environment and that was not accounted for within the MHAQ itself. Rather than estimate how far or how long she was able to walk, she estimated her ability to walk outside in terms of a specific local landmark (the name of which is omitted for privacy reasons), as illustrated below when the respondent was interviewed in her home community.

Q: “Walking outside on flat ground. Not a lot of flat ground around here. Any problems with walking outside? Could you walk from here to the Northern?”

A: “No.” [laughter]

Q: “That’s a problem. Because I think to the Northern would take about 15 minutes to walk?”

A: “I think so. It would take me an hour to get there.” [laughter]

Q: “It would take you an hour, OK.”

A: “But, you know what, I notice there’s a lot of difference when I’m in the city, I walk lots. I walk, walk, walk.”

Q: “Where it’s flat.”

A: “Yeah. It’s easy. That’s what I noticed.”

- Q: "So here, where it's bumpy, when it's up and down, it's constantly curving and rolling...How far do you think you could walk here? Or how long? If that's an easier question."
- A: "From here to, I can... cause when I came here, I walked to the Mxxx store and I came back."
- Q: "To the Mxxx store. Where is the Mxxx store?"
- A: "Just across the road. Three, four houses down from here."
- Q: "And so that was OK."
- A: "Yes."
- Q: "Could you go much, much further than that?"
- A: "Maybe." [laughter]
- Q: "So that's only about 10 minutes."
- A: "Yea."
- Q: "On the ground here. OK. And yet you wrote 'no difficulty'."
- A: "I don't know."
- Q: "Because in Winnipeg you have no difficulty. Well. So it's interesting. So the walking... it depends on where you are."
- A: "Yea."
- Q: "But you've... how come you filled it out the way it is in Winnipeg instead of where you live?"
- A: "I don't know, because I'm there most of the time too."
- Q: "Because your husband's there?"
- A: "Yea. Like I go there maybe every two times, two times a month. And I walk lots."
- Q: "Here about 10 minutes."
- A: "Mmhm."
- Q: "OK. It's interesting because on this questionnaire, they don't say..."
- A: [chuckle]
- Q: "You give us one answer for Winnipeg and give us another answer for St. Therese Point"
- A: "I don't know, I don't know why I chose that."

Alternatively, other individuals reported their ability to complete an activity without accounting for the relevance or meaning to their own situation. This was particularly apparent when reporting on the ability to manage shoelaces in a community where people have adapted their dressing habits to accommodate a muddy environment, regardless of capacity. As one participant admitted, "I don't think anyone

ties their shoes here.” The researcher verified this observation. Among northern health care workers, they had a pair of “inside” as well as “outside” shoes because of the muddy conditions in northern communities. There, it is common practice for individuals frequently coming and going to leave one’s shoes loosely tied up to make it easier to remove shoes on entry and to put them on at exit. As well, it was common to avoid shoes with laces completely. This approach to living with RA in the north was highlighted by a 54-year old female who responded “1-with SOME difficulty” to being able to “dress yourself, including tying shoelaces and doing buttons” and offered the following explanation.

A: “I can’t really do buttons right now. But I can, like, I can tie (shoelaces)....”

Q: “So you are able to undo your shoelaces and do them up”

A: “No, I don’t; I never untie, I never untie these... Because of... with the mud. Yea, it’s easier for us to do it like that.”

The importance of understanding context and how it influences responses was also apparent for the question item on ability to wash and dry your entire body, or turn regular faucets on and off. In communities where many of the homes still have no running water, individuals report on what they *can* do in a controlled environment, not on what they actually do or *how*. A 67-year old woman responded with a “1-with SOME difficulty” on her ability to turn faucets on and off; yet her home had no running water. Another female participant who responded “0-without ANY difficulty” to the same question explained her situation as follows.

Q: “The next question was washing and drying your entire body. I have to ask you, do you have running water in your house?”

- A: “No, it’s CMHA [Canadian Mortgage and Housing Association] housing but my house burned down two years ago and they didn’t really... really fix it yet. And I’m still waiting on it, like I’m checking them where they are. And they said we don’t have much material to do your house. We have no funding and all that. And it’s poor. It’s hard for me to do everything in my home too.”
- Q: “Like that...so washing and drying your entire body, how do you answer that if you don’t have running water?”
- A: “I have to go to the nursing station and take a shower.”

From these responses, items measuring capacity related to washing and turning water on are not always interpreted in the same manner where there are issues of access to water. While many homes in northern remote First Nations communities remain without running water, this particular community has since experienced significant efforts to provide water to individual homes. These developments may shift the way individuals respond to activity items in the future, thus impacting response meaning. In other words, future response shift may have more to do with environmental change than disease activity *per se*, and may complicate the clinical interpretation from one visit to the next.

Enabling Modifications

Further incongruence between the MHAQ questionnaire responses and how participants described their ability to execute a task or activity was apparent when they made reference to their use of aids, adaptations or assistance from others. These modifications, which enabled individuals to act independently at home, were unaccounted for in the questionnaire and were only discovered with further probing.

One woman who scored her own ability to get in and out of bed as “1-with SOME difficulty”, explained that she could only do it with her husband’s help. The form did not explicitly ask whether or not assistance was provided to perform these activities; that being said, her response was accurate for her situation but was an incomplete representation of *how* she was able to perform the activity.

Getting “in and out of a car, bus, train or airplane” provides another example of how participants interpreted capacity and performance. A 41-year old female who responded “0-without ANY difficulty” described her process as follows.

“I have to go a step up, use one leg to go up. Do you know what I mean? Two feet on each step. Yea. I just lift my leg up like that and use the step with this one and bring this one up.”

A different female, 67 years old, who responded "1-with SOME difficulty" to the same question, explained, “We have a stool. And there's a rope. And I put it down and I step on it and take that thing.” While a 24 year old female with the same score clarified “I use my cane to help stabilize me.” Without prior explanation or adequate probing, the responses given are misleading. For instance, health care providers may overestimate the level of independence of an individual and underestimate the impact of RA on a person’s ability to participate in meaningful activities. The measurement of activity limitations using a summary approach of select activities of daily living as illustrated by the MHAQ misses the need for enabling technology or the impact of environmental barriers on daily living.

Missing Elements

Further into the interviewing process, it became evident that three key elements were missing from the MHAQ questionnaires, which had great meaning and relevance to the participants. They are hair care, getting in and out of a boat, and mental health.

Hair Care

The two MHAQ questions specific to self-care include dressing (doing buttons and tying shoelaces); and washing and drying one's body. While those activities are arguably very important, the act of managing one's own hair, especially long hair, can be a very important element of self-care and may have even greater meaning for some individuals. Equally compelling was the dependence on assistance to manage hair, a very personal activity for many individuals, requiring a combination of hand agility and shoulder movement. A 31-year old female living in northern Manitoba expressed her activity limitation in hair care as follows.

- Q. "Is there anything else you wish you could do that you can't because of arthritis?"
- A. "Put my hair up like I used to...I was growing my hair, it was up to about here and I had to have my husband cut it out, cut it for me. And he did cut it and put a pony tail. It's easier. And I brush my hair so I don't have to go all the way down straight."

A 49-year old female with RA described the assistance that she was able to provide in the care of someone else's hair.

"My friend used to come and see me and she'd be like this and she'd bring her brush. 'Can you brush my hair?' That's when she had it long. She's got short hair now. So I used to sit there and I used to brush her hair; have coffee with her. And sometimes she'd be just totally bed ridden."

By not exploring this activity, health care providers may not grasp the full limitations of activity experienced by an individual or their need for assistance for completion.

Boat Transfers

Getting in and out of a boat is essential for community travel and participation in community activities for individuals living in St. Theresa Point and any other northern community where water transportation and activities are the norm. At the time of the investigator's visit to St. Theresa Point, "Cultural Days" were being held in the community whereby all families were encouraged to visit their traditional fishing camps. This activity alone necessitates getting in and out of a boat either at a fixed-height dock (that is, the docks do not adapt to a fluctuation in water height) or at a beached shoreline. Many individuals commented that they were no longer able to manage activities related to boating without some sort of help. A 37-year old female, who answered "1-with SOME difficulty" on the related question in the MHAQ, described her challenges as follows.

"I only (have difficulty) when there's... the water's really shallow. That's the only (time). One time I got stuck in a boat; I couldn't get out. The dock was very high; I couldn't get out. They had to go to the shoreline. I told them like, I, sometimes I can't touch my knee on the, you know, I seen people crawl out from the boat."

Another female participant with a similar MHAQ score of "1-some difficulty" on this item went on to state "I have a hard time going (in and out of a boat). Maybe three men sometimes they haul me up and I scream at them, 'Don't do it like that! Don't do that!'"

Another individual with a score of "0-without ANY difficulty" stated: "I don't have any

difficulty. Only, yea, I do when I mention that, but not, (I'm) very not, um, helpless, because my husband helps me."

Despite the difficulty of getting in and out of a boat and its relative importance in this community, many individuals did not include boats when reporting their ability to get in and out of vehicles. Where the word "boat" is not included in the list of "car, bus, train or airplane" (Appendix 1, question 1.h), people do not reflect on that aspect of vehicle transfers. They limit their responses to the examples provided in the question, as illustrated for the items on dressing and washing that excluded hair care.

Mental Health

While the MHAQ focuses entirely on physical activities, how mental health impacts the execution of an act or task is absent in these assessments, as noted by several participants who talked about depression and stress. A 46-year old former health care aide now on disability stated that a question on depression was missing and went on to describe how arthritis impacts her life.

"Well for one thing I can't work. I guess I could if I would train in something else but I just don't have the energy sometimes just to get out of bed. Um. Depressions, a lot of depression comes with it."

Another participant reported on how she handled the stress and depression that comes with RA: "Sometimes I just close my door and just close my eyes, cover myself, relax and try to throw it out of the window or something." By not including mental health clinicians are not able to assess how it interacts with physical activities at the individual level or participation at the broader level. .

5.2 Thematic Analysis

A thematic analysis was then undertaken to expand the understanding of the impact of RA on the daily lives of First Nations persons. Using the ICF as a conceptual framework, issues of impairment, activity, participation and contextual factors were specifically explored. Applying the ICF lens in this context, the investigator identified three themes: *Ka-wachi-wa-pinaywin* (Oji-Cree for “coldness in the bones”); *Adaptive Resilience*; and *Family Relations*. Various sub-themes were also identified and these sub-themes and definitions of all terms are listed in Table 11. The first theme is the only one exploring the explanation of the impairment, while all three themes explore participation. Capacity and performance of activities and tasks are addressed, while contextual factors, both environmental and personal factors are considered.

Table 11. Key Findings of Thematic Analysis

Key Theme		Definition
1.	<i>Ka-wachi-wa-pinaywin</i> ("Coldness in the bones")	This term relates to the traditional understanding of arthritis and how it impacts the participation in traditional activities in the Island Lake area.
1.1	Explanatory model of RA	Individuals had personal explanations for the causes of RA balancing hereditary with activity / environmental approaches.
1.2	Environmental impact	The impact on living in a remote community with RA has unique environmental challenges.
1.3	Participation in traditional tasks	Individuals have had to learn to strategize in order to continue with traditional activities and tasks such as berry picking, fishing, hunting, & trapping.
2.	<i>Adaptive Resilience</i>	This term acknowledges the strength and resolve that individuals with RA described in response to the fluctuating and slowly deteriorating levels of activity and participation characteristic to RA.
2.1	Reluctance to ask for help	Individuals expressed reluctance to ask for assistance in personal activities (e.g. ADL and mobility).
2.2	Facilitated participation	Individuals need to accept help in order to participate in family and community events.
2.3	Acceptance of disease	Over time, individuals have accepted the fact that RA is a part of their lives but may necessitate assistance in completing daily activities.
3.	<i>Family Relations</i>	This theme considered the impact of RA on an individual's role within the family and his/her relationships to other family members.
3.1	Cost of RA	Attitudes towards an invisible disability and frustration with a change in ability and fatigue have challenged many relationships.
3.2	Relationships of support	Relations with spouses, children, parents, and/or siblings are strengthened through acceptance and mutual interdependence.

Ka-wachi-wa-pinaywin

The term *Ka-wachi-wa-pinaywin* in the Oji-Cree language of the Island Lake people of Manitoba refers to “coldness in the bones” (Fricke, 2015). This term was chosen to represent a theme relating to and honouring the traditional knowledge of participants. The phrase captured the nuances of living in a remote northern community while straddling the challenges of a traditional lifestyle with the desire for modern conveniences and technology, in a physical environment not easily adapted. This term illustrates Oji-Cree explanations and understanding of the cause of RA, the influence of the environment on living with RA and the impact of RA on the participation in traditional activities.

Explanatory model of RA

The meanings of chronic illness, as reflected by *ka-wachi-wa-pinaywin*, are created and transformed by a person with his or her family to represent a cultural experience (Kleinman, 1988), understood only within defined contexts of meaning and social relationships (Kleinman, 1980). Medical anthropologists transformed such phrases into explanatory models to describe subconscious personal beliefs used to make sense of illness (Kleinman, 1980; McSweeney, Allan, & Mayo, 1997). In this study, a 34-year old woman studying to become a teacher was the first individual to use Oji-Cree to describe RA. She spontaneously used the phrase *ka-wachi-wa-pinaywin* and explained that “it means you're sick from the coldness; it's cold into the joints”. This term was used by other participants to explain what they believed to have contributed to the

cause of arthritis or the stiffness associated with flare-ups. A 58-year old former trapper and fisherman explained how his arthritis was likely related to his cold exposure.

A: "Well yea, that's what I heard these old, uh, old trappers used to, used to trap all their lives...And used to sit in the snow and, you know, when they set their traps and stuff like that...That's where they got it from. The coldness from the snow and stuff, water and all that."

Q: "On their knees."

A: "Yea. Even my, even my wrists they act up right away when it's cold in the fall, right? I can't do anything. It's the cold that makes this. I was growing up... when I was a kid, I was always, I had, you had to walk. You had no bus to go to school. And it was across the lake. We had cold feet and everything going across every day. I used to go to school there and back. And it catches up with you later in life I guess."

An additional respondent related her condition to cold in this way. "The weather has a lot (to do with it). Not like moisture. A lot of people say moisture but for me it's not moisture, it's the cold. When it's cold, I'm very limited." The weather seemed to have a significant impact on many individuals, sometimes leading to increased joint pain and sometimes to a general feeling of fatigue. A 42-year old male from the north described the impact in this manner: "Sometimes I get tired. Uh, you know how when you have that grey grey sky, like it's grey all day? Sometimes that affects me. I would get tired."

Several participants when asked directly about what caused their arthritis stated that their arthritis was inherited from a family member: "Well, my mom, my mom has arthritis so I'm thinking that it runs in the family, my mom's side." A 41-year old female living in St. Theresa Point answered in this fashion.

- Q: “What's your understanding of why you have arthritis? Why do you think you have it? Or how did you get it?”
- A: “Probably through my mom. There's a lot of arthritis in my mom's side of the family.”

Many participants recognized the genetic link to arthritis, which is not surprising given that the community was participating in a study investigating the early identification of RA and how it is expressed within certain family members who have biomarkers suggesting a risk for the disease. With risk came guilt. One young woman expressed feelings of parental guilt, when she suggested that her “mom blames herself or something.” Although the biomarker study promoted another way of understanding cause, participants still expressed the belief that cold exposure may have put them at additional risk. The straddling of an Oji-Cree explanatory model with that of a western disease causation model demonstrated how multiple understandings are present in these communities and that the impact of weather and the environment on disease progression and management should be assessed.

Environmental impact

The impact of weather and the physical environment where there is no central heating, no air conditioning, no paved roads or sidewalks can have a significant impact on the ability of an individual with a chronic condition to fully participate in the community. The following is a description provided by a 55 year old man from St. Theresa Point.

“It's hard to walk. See the condition of this place, this reserve. You know, it's hard with all these potholes and everything, walking and everything. The boat, getting across on the dock and getting off, off and up. Getting on the plane, you know. It's pretty difficult for me.”

A 34-year old female explained how operating common modes of transportation in her community were made difficult by her arthritis.

“I go around visiting. I walk. I can’t even drive a 4 by 4, the ATV. When I drive, my fingers will be very puffy, like a reaction. One time I couldn’t even press on that ATV.”

A 55-year old man further expanded on limitations arthritis created for this activity.

Q: “You wrote that you can hardly do any of the things that you want to do. What’s the kind, what are a few of the things that you really miss being able to do?”

A: “Drive a boat.”

Q: “A boat.”

A: “Yea. Could be just to drive around all over the place, what I used to do, you know. Walk in the bushes. I did that lots. Now I can’t even do that anymore.”

Q: “It would be very hard to step over a log.”

A: “Yea. Pretty hard. Not over a log this big. That’s what I miss.”

Q: “Uh, huh.”

A: “It’s something I have to live with now.”

Getting in and out of a community where the airstrip is located on a different island has made travel to other communities a challenge. St Theresa Point is an island of bedrock only accessible by air and requires transportation from the air strip to the island by boat in the summer, helicopter at fall freeze up and spring thaw, and by ice road in the winter. The physical features of this community have made the installing of water and sewer pipes to all homes difficult. Those that have recently received running water however noted that while there were benefits it had a negative impact on their disease. For instance, one individual noted that having running water in her home in the past few years had actually reduced her daily activity levels.

Q: "That must have made a big difference to you in your life having running water (for the last 3 years)."

A: "Sort of good. In a good and bad way."

Q: "How in a good way and how in a bad way?"

A: "In a good way, it's easier to do laundry. In a bad way, I'm not really doing much physical labor. Feels like I'm getting... doing less work, less physical stuff. I must be weak. (chuckle) That's how I look at it anyway."

Despite the disadvantages expressed by this 41-year old, most participants welcomed progress made on getting running water, whether it is from a central water line or from a cistern or holding tanks located outside every home. For this community, installed water systems did not always mean having a sufficient quantity of water. For instance, individuals with RA are encouraged to soak and move their hands and wrists in warm water or to apply ice packs to swollen and warm joints. Having water on hand and having ways to have heated water can pose another challenge. One participant stated that a water tank could last his family of four two weeks before needing to be filled; the average cost to the family of re-filling the water tank, however, is fifty dollars. If you don't have the monies to pay for a refill because of income insecurity then the tank is not filled. While such advancements in accessible modern amenities common in southern urban settings continue, access is still a barrier for some. Modernization, while beneficial, can also displace previous activities that helped individuals living with RA keep their joints active.

Participation in traditional tasks

In the Island Lake area, berry picking, gardening, fishing, hunting and trapping were common subsistence tasks. For many complex reasons associated with colonialism and modern technology, reliance on these tasks has lessened over time. These tasks

have remained, however, important features of community life in the region. Events such as Cultural Days and the maintenance of family fishing camps have contributed to on-going interests in maintaining some aspect of traditional tasks. Where individuals with RA have not been able to modify their environment or negotiate assistance, it has meant a loss of participation in some of these events. A 56-year old man, who answered “1-with SOME difficulty” on the MHAQ question on walking outside, explained how he could no longer go onto his trap line. “Not any more...I can walk (at my place on the lake). Well, there's no logs like back in the bushes....I'd like to be... I like being outside.”

Limitations in other traditional tasks were also apparent. A 56-year old female described her difficulty in traditional beading: “My mother-in-law tried to, like she tried to get me doing the beadwork again. That is hard to get the pins and the needle and go through the hide, ... moose hide.” A 41 year old woman also lamented over the tasks that she was no longer able to do. “Sewing, embroidery and beading. Those are... I can't do it anymore. In a good day, yeah, I can do some beading. But it's the next day, I pay for it.”

Alternatively, some people have managed to strategize and cope with deteriorating levels of ability by, for example, getting assistance from family members. A 58-year old man described how he occasionally gets help from his brother so that he can continue participating in his meaningful life tasks.

Q: “Question #3 was which, which of the following best describes you today? You checked off “2- I can do most of the things I want to do but I have some limitations.”

A: “Yea, like the turning of the, opening stuff.”

Q: “Opening stuff with your left hand.”

- A: "Or anything like that, like I have a hard time, trying to be a mechanic and I can't do those screws or big bolts, bolts, stuff like that."
- Q: "Well, and so being a trapper, do you go out on the trap line alone or do you go with somebody?"
- A: "Uh, I usually go alone. Sometimes my brother, I go with him."
- Q: "So do you... how do you manage out on the trap line by yourself with your arthritis?"
- A: "You know when I, when I, went and set traps, I went with my brother. So sometimes I, I got this tool that you press and it, you sort of sit your toe with that."
- Q: "OK."
- A: "And then I use that. And sometimes I tell my brother to do it for me."
- Q: "Because of your wrists?"
- A: "Yea."
- Q: "Is your brother a trapper on his own?"
- A: "No, yea, he's on a different trap line though. But I told him to come and help me this one time this fall. And when I go check my traps, I don't, I go alone because there's..."
- Q: "So can you open the trap and?"
- A: "No. When I kill something, I just bring it back like that with the trap."
- Q: "With the trap. OK."
- A: "Yea. And I use that tool and set it back in."

Participating in meaningful traditional tasks is an important means of maintaining one's culture, and for some individuals, it may facilitate coping with the changes associated with RA. An individual with long-standing disability secondary to arthritis shared her personal reflections of the Seven Sacred Teachings: Truth, honesty, humility, respect, love, courage and wisdom. Her on-going exploration helped create a platform from which she could connect with others in similar circumstances and to develop strength in community. The current mechanism of ascertaining limitations in activity through the MHAQ questionnaire does not permit an interrogation of how someone is pursuing culturally valued activities. Quantitative measures make it impossible for clinicians to understand the complexities inherent in performing certain

tasks. Beyond the MHAQ, details about restricted participation in traditional tasks are dependent upon the expertise of the health care provider. Providers would have to gain understanding beyond clinical training to fully appreciate how these participants are limited in performing common tasks unique to their community.

Adaptive Resilience

Just as individuals have adapted to progressive impairments related to RA, so do individuals have to adapt their behaviour to live “well” with this condition. Some individuals described an on-going reluctance to ask for assistance, while others described assistance as critical to maintaining activity and participation. To cope with the change, study participants have developed an inner fortitude and resolve. This resilience in the face of advancing disease is described below. A 42-year old man described the impact of RA as follows.

“I just can’t do it, do things right away. Some things I can do if I’m okay, I can do right away. And some things I can’t do ‘cause I have pain....That’s what I noticed now. That if I do anything, it takes me longer. But I get it done. Not like the way I used to be when I was young.”

This individual acknowledged that through perseverance he now gets the task done. A woman 41-years of age from northern Manitoba explained her dilemma in the ensuing way.

“Sometimes that's what gets to me the most... fatigue and knowing it's not going to go away. That's what's hard about having arthritis to me. Knowing it's not going to go away. Not going to get better. The hard part about this year is

learning to do things different and accepting that I can't do things the way I used to.”

To live on, individuals needed to accept their diagnosis and fate, even if they were not initially aware of all the implications of a diagnosis of RA. While RA education materials describe RA disease progression, this description is someone else’s narrative. Only they alone were able to understand what they can and cannot do.

Reluctance to ask for help

Although some activities and tasks were acknowledged as particularly difficult to complete independently, some participants described not wanting to burden family members or friends with their limitations or unmet needs. As one northern respondent said, “I try to do things on my own. I try not to rely on people. Like if I can, it takes me long to get in and out of vehicles and boats but I do it myself.” Another respondent living in Winnipeg stated, when asked if he ever seeks help from his family, that:

“It depends. But uh, I'd rather not bug them. I just do it on my own. I don't hardly bother them much, eh? Mostly like, every once in a while, but not for favours. When it comes to favours, no. I tend to do things on my own as much as I can unless it's, unless it's vehicles, then you know, I'll give them a call. But other than that, no.”

He preferred to remain self-reliant than seek any sort of help. Another person who worked at retaining her independence did so by hiding her limitations from her colleagues by going to work before her co-workers would arrive.

“For the past month it's been hard because of the pain in my hands. It's hard to type and I don't like it when people know I have arthritis so it's mostly... I do my notes before people come in because I can't really hold a pen. So I do my notes, make other appointments, before they come in.”

Individuals spoke about their reluctance to ask for assistance from those around them, but it was unclear from where this reluctance stemmed. For some, it emerged in their childhood when the joint pain first began and those around them were not forthcoming in providing any support. This 67-year old woman described the response she received to her joint pain while in residential school.

Q: "When did you start having problems with your joints?"

A: "I was, it seems like when I was in...I was sent to school in (C), that was...I don't even know the year."

Q: "Were you in elementary school, a little girl?"

A: "A little girl."

Q: "Oh, it started really early."

A: "Yea. I think I was like that and the nuns used to tell me that I was faking it and I didn't, didn't give me any medicine or anything..."

This past experience of asking for help but not receiving it may have prompted a reluctance to ask for help. It could also be out of pride or not wanting to be a burden to family members. Another possible explanation is the unanticipated change in one's family role or responsibilities as RA progressed and then the lack of clarity as to how and when roles should change or reverse. A 56-year old woman described how she felt when she was faced with this challenge.

"That's really frustrating. Sometimes when I can't cook or do laundry because I'm supposed to look after the grandkids and my husband cooks for him. He cooks for me. Does laundry sometimes too. But it makes me feel that I should be the one, not him."

The transition to a new role in which the expectations are no longer as they have been may be subtle without explicit permission from partners or family members. Yet participants described the evolution of their roles over time, with what often seemed a

sense of pride in the new tasks adopted by family members and the support they provide. This is demonstrated in the following section.

Facilitated participation

Given the progressive nature of RA, continued participation in the home and broader community necessitated an acceptance of support from others to complete certain activities and tasks. Individual participants described the physical and emotional support that they received as primarily from spouses and children. As one older woman voiced:

“Your husband is your partner, and he helps you. And if he wants you to be better...I bet you if I wasn't looked after by him, I would just be in bed. No exercise, nothing. But he gets me. Sometimes he knows when I'm really bad, like, when my arthritis is acting up. Because you get those moods. You want to sleep. You want people to leave you alone. But him, he just gets me up and takes me out on a ride. I bet you if it wasn't for him, I wouldn't be like this.”

Another woman described how her partner helped her cope.

“And then he starts talking about, telling me about stories from a long time ago and that relaxes me. Childhood days being out in the bush, stuff like that. Tells stories. And it relaxes me.” [chuckle]

This 56-year old man depicted how the assistance of his son allowed him to continue participating in meaningful tasks, while still maintaining an element of his former position as a successful hunter and fisher.

Q: “The next question here is, that you can do some but not all of the things you want to do. And you have “many limitations”. What are the main things that you wish you could do that you can't do anymore because of your arthritis?”

A: “Go wood cutting. Hunting, fishing. Lots of stuff.”

Q: “Traditional stuff.”

A: “Yea.”

Q: "... and so hunting, if you can't hunt yourself, do you still go on the land with your son or a friend or someone?"
A: "Yea, yea. I go with my son, yea."
Q: "So he does the shooting and you go?"
A: "Yea, he does the shooting."
Q: "But you're still part of it at least?"
A: "Yea."
Q: "Do you still have a lot to teach him or can he do it all on his own?"
A: "He can do it on his own now."
Q: "OK."
A: "Yea." (pause)
Q: "Does that bother you that you can't do it all by yourself anymore?"
A: "Yea, it bothers me." (pause)
Q: "Same with the fishing?"
A: "Yea." (pause)
Q: "Hm. Has that changed your relationship with your son? Now he's the one in charge of those things. And you get to, hopefully you still supervise him."
A: "Well I tell him just what to do, yea."
Q: "OK."
A: "I'm the boss there." [chuckle]

The tasks within which some individuals were engaged likely contributed to their self-identity within the family unit. For some individuals, like the man above, he was able to maintain his role to some degree by exerting control over his situation. Other participants like this 23-year old woman described reluctance in accepting help for a task that is intermittently manageable.

"Some mornings when I can't get my hair up or if I can't brush my hair, my mom usually grabs my hair and starts making it. It's embarrassing when she does that."

For this woman, RA has caused her to be vulnerable to her own body's fluctuations.

What should be a normal expectation in a young woman - to care for one's own

appearance - has been compromised by inflammatory joint disease. By receiving the help of her mother, the performance of self-care was facilitated but reluctantly.

Acceptance of disease

Accepting assistance and support to counter the disablement process appears to go hand in hand with individuals accepting the impact of RA and all its uncertainties and fluctuations. This is illustrated in the statement below from a 41-year old woman.

Q: "How do you feel about the future living with arthritis?"

A: "I have to find a way to live with it. It gets to you sometimes knowing it's not going to get better. But you have good days and bad days. It's good to have a sense of humour too, good family, good kids.... Accept it. You have to accept it as part of your life....At first I was in denial... and when you accept that, it makes it easier in your mind because all of a sudden, it's not scary. It's something you have to face."

This woman, too, seems to have reached a point where she and her family have accepted the presence of a chronic condition, despite being only 39-years old.

"They (family members) accepted it. Everyone accepted it, even me. We just go on our days. They just accepted it and I told them not to be sad about it. And I'm not sad about myself."

The point at which individuals accept their disease and its impact on their lives may fluctuate over time and will vary from person to person. Health care providers are well positioned to help by engaging individuals in dialogues that facilitate this transition to accept life with RA.

Family Relations

Participants described the impact of living with RA, its associated joint pain, fatigue, stiffness and limited activity on their relationships with their spouses, and sometimes parents. The impact on relations with children was particularly poignant. One 46-year old woman described an instance when her son, who was eight years old at the time, asked her questions about RA and began to cry.

“One day we're talking about it and then he laid beside me and he's thinking about it. All of a sudden, he's crying really hard.”

Alternatively, another mother (and grandmother) described the strength that her five children have gained from her experience living with RA.

- Q: “Any other stuff that you can't do because of your arthritis?”
A: “Yea, I can't really hold my grandson. He's a month old.”
Q: “Oh. Is that your only grandchild or do you have more?”
A: “I have a, one, one of them will be 2 years old in February. And I have a one month old grandson.”
Q: “Nice. But you can't lift him up?”
A: “Not all the time.”
Q: “If you're sitting in a chair, can you hold onto him?”
A: “Yea.”
Q: “It must be really hard not to be able to interact with your grandson the way you want to.”
A: “Yea, it's hard when, I'm too scared to drop him....”
Q: “So with your arthritis, has that impacted your relationships at all?”
A: “Yes. I do a lot less. But it's, it gets my kids to do things for themselves. But at the same time, they have to help me a lot. And they're used to it; they're used to how I am. Stuff I can't really do anymore. Like they'll help me carry groceries. Stuff like that. And they always make sure our steps are clear so I don't slip and stuff. But they also know I don't like it when they see me when I'm hurting. In the mornings, when it's really hurting, like for the first 3 hours sometimes, I cry like for an hour. I just I just go lock myself in a room because I don't want anybody to see me like that. I don't talk when I'm hurting because I say mean things sometimes when I'm like that. Overtired. I don't like... the way I've been so long is I do things alone. I worked hard taking care of my kids, my husband. And all of a sudden I have to ask for help almost daily. So it's been hard.”

Q: "Do you think you'd be a different kind of a mother if you didn't have arthritis?"

A: "Uh huh. Yeah, I don't like, I don't like how it (RA) affects my kids sometimes. Well there's good and bad. It teaches them to be caring. Be perceptive of people, how they feel maybe. Why they're not talking. So they learn a lot. They know what to do too when I have bad pain in my hands. My wrist was really hurting last week. My son went and got snow and puts it in a Ziplock bag and put the bag here... It's like putting ice on the fire..."

Another respondent described the key message that she hoped her children would gain through her own experience of living with RA.

"I want to show them (my kids) that anything can be accomplished with whatever's in your way. Whatever obstacles in life that there are, that you can get through them."

The challenge of straddling the role of a strong mother to one who is living with pain is difficult as articulated below.

Q: "Anything else you want to tell me that we haven't touched on that you think is important?"

A: "Uh... no. Well, you said, tell, you know what, I'll tell you something. What, when I found out that I had arthritis, the pain and everything, I used to hide it. I used to go in the corner and cry because I didn't want my children to know how painful it is. I used to go like that. "

The impact of a chronic disease such as RA on the relationships between those affected and those providing support can unfold as either positive or negative. For some participants, relationships seemed to grow stronger, while for others it was sometimes too much to bear.

Cost of RA

Because disease activity is not always visible, its subtlety in presentation can lead to miscommunication and frustration in daily relationships. The cost of trying to hide the

pain, stiffness and fatigue of RA sometimes has had a negative impact on close relationships, in particular with spouses, as described by one participant.

Q: "How satisfied are you with your ability to do your usual activities? You said 'somewhat dissatisfied'"

A: "I wish I could do all those things that I, um, I was supposed to do at this age. You know what I mean? People say, come on, you're just not an old lady yet, you know? ...Not my friends. I guess my husband saying, 'Come on, let's go'. And I say, when I say, 'I can't go away' or whenever he wants me to go with him. Because I know he's going to be gone for a long time somewhere with visiting his family or whatever. And I, I don't usually feel up to it. Or even when he says, like, when he sees something immediately. My kids drop something on the floor and he said, 'why don't you clean that up?' And I said, 'I can't right now; I'm just taking medicine right now.' 'Come on, you're just, you're not an old lady yet.' You know what I mean?"

Q: "That must be hard."

A: "Yes it is."

Q: "Has the arthritis affected your relationship with your husband?"

A: "A little bit I guess. But I don't want to make it affect it. I don't want think about it too much. It only affects you if you let it...That's why I always, I always think with my husband, I wish he can believe me."

Another young female participant described the difficulty her marriage endured because of arthritis.

"A few times me and my husband argued about, like, my arthritis. The one time, he was like teasing me and everything. Like we almost broke up from it, from my marriage. And then we started arguing and this and that because I didn't help myself up. I just lay there....There were times we were arguing, me and my husband. Then I don't know, I was just like really helpless."

The toll that arthritis took on relationships was expressed in many different ways, and for some, it meant the end of the marriage as described by this 46-year old woman.

A: "I can still bathe myself and toilet myself... my daughters used to have to do that for me like."

Q: "What was that like? Did that change your relationship with your daughters?"

A: "No, they were actually really good about it. I guess, uh, it changes the relationship I had with my husband though because he didn't really fully understand it. So he wasn't really there, supportive like. ... We're separated though, just because he couldn't understand really what I was going through. He would say I was lazy and stuff like that. And it's kind of hard to talk about...I guess he's just starting to realize now because our daughter was diagnosed with RA too."

For others, a marriage could endure but not without its challenges, as articulated by this young woman.

Q: "Sometimes people with arthritis, they've said that the arthritis has really affected their relationships as well, with their husband or wife or with the kids or with their mother. Relationships. Has that had an effect on your life?"

A: "Sometimes it's like, um, my husband, when he helps me a lot when I have pain. But sometimes he gets over tired and gets fed up I guess I would say. But I don't really know how to explain it right now. Like, right now, it's like I got no pain. He's not feeling any worries or anything. But sometimes I just tell him I'm just tired of this pain I've been having. And I get migraines too from the weather and all that... It's so, when I have the pain, it's so stressful. But when I don't have the pain, that's when everything goes happy. Nothing's wrong. Like when I have the pain, 'oh no', that's what they think. 'Oh no, mom's sick again. Oh no, we have to do everything for her now' and all that."

The impact of RA on relationships is tangible as evidenced by the numerous narratives of the participants. Fortunately, there were also instances of supportive relationships, both with children and with spouses.

Relationships of Support

Several individuals described the comfort and support they received from others, primarily from their spouses. The assistance they received was not only physical but also

emotional. The following narrative is from a young woman who must now rely on her husband for hair care:

“My husband’s my hairdresser too... He dyes my hair... He braids my hair... He does my hair because I can’t comb the back or go upside down and put my hair up right there. “

During part of this exchange, this woman insisted on sharing a digital picture of herself, showing her husband doing her hair; after the interview, she came back to introduce her husband with a look of pride on her face. Another participant described the relief his wife tried to provide for his physical discomfort and pain.

A: “I’m so used to pain now”.

Q: “Do you tell people that you’re in pain? If they ask you how you’re doing, do you say, ‘actually, I’ve got a lot of joint pain’? Do you hide it or do you tell people?”

A: “I don’t ...sometimes I tell them. Sometimes I just say nothing. Because that’s how my life is going to be now. So..”

Q: “Do you tell your wife how you’re feeling?”

A: “Yea. She knows my pain. She, uh, helps me, helps me now. Like when I have a pain over here, she usually goes to the kitchen and takes a towel or small towel and then she heats it up some and she puts it on here. And then she rubs me. She covers me with a blanket so the heat will be there.”

Emotional support was also described as coming from both the community as well as a spouse as described by this older woman.

A: “... then I started telling my husband (about the pain) because he knew. He didn’t ask me. He knew because I guess he seen me, eh. And then one day he told me, ‘you shouldn’t hide it...your pain. I know when you're in pain’, he says. ‘You know, you should tell, you should tell so people will know’. But I told him, ‘I don’t want anybody else to know how I am. I want to be treated the way I always was treated. Like ‘I’m no special person’ I told him. So now, after a couple of years, I’ve been going to church every day and that’s how I got my, my mind. It’s peace some more. I feel peace now.”

While the support from spouses was often well intended, one young woman claimed that she also needed a reprieve from all the attention:

A: “It's just that he is very supportive and he helps me with the kids. But sometimes I would just yell at him, like, ‘can you get out of the house?’”
(chuckles)

Overall, the physical and emotional support from family members and the community was viewed as necessary for the participants to live independently. In order to be active and participate in social and traditional tasks, individuals with RA relied heavily on the help of others. Without distinguishing the level of assistance required or used, the MHAQ as a measure of functional status does not capture an individual's true capacity and performance.

5.3 Summary

Qualitatively, we discovered how and why participants completed the MHAQ as they did. We gained an understanding of the barriers to completing the MHAQ; how patients interpret questions thus impacting clinical interpretation; why items were missed; whether the items measured are capturing actual limitations; and whether the measures have any relevance to certain community members and the contexts in which they live. From the directed content analysis, missing or multiple responses to the questionnaire were explained by a lack of clarity in the question or a fluctuation in their RA status. There was no particular pattern to missing answers although the Visual

Analogue Scales appended to the MHAQ questions generated confusion among a few participants. Some preferred a numerical answer on a scale of 1-10 in place of visual line scoring. Probing the responses to the MHAQ exposed many examples of contextual incongruence between the written responses on the MHAQ questionnaire and the oral narrative of how, when and why an individual acted and performed the way he or she did.

The findings from the thematic summary focused on the impact of RA on the activity, participation, and daily lives of the participants. Three key themes emerged: *Kawachi-wa-pinaywin* (“Coldness in the bones”), *Adaptive Resilience*, and *Family Relations*. Within the first theme, a traditional lens explored cultural experiences of RA, the impact of the environment in a northern community, and the ability to participate in traditional tasks. From a resiliency lens, we discovered that participants were initially reluctant to ask for assistance but once they accepted their condition, the help they received was welcomed. In the theme on familial relationships, individuals described both the negative impact of RA and also the positive outcomes on their relationships.

Overall, the narratives provided an understanding of activity and participation beyond rankings provided by the MHAQ questionnaire. Several key aspects of activity and participation are not measured but are relevant to RA affected First Nations. They include the the environmental context (e.g., getting in and out of a boat; walking on uneven dirt roads); the impact on traditional tasks (e.g., caring for long hair; hunting and fishing); and the intertwining of activity, participation and mental health (e.g., stress;

depression). In short, the MHAQ as demonstrated quantitatively may be a useful screening tool but when adapted to a local context or group would provide more relevant and more meaningful information to bridge the understanding gap between the clinician and First Nations patient. To do so we require additional measures to fully understand the impact of RA on the performance of meaningful activities, participation and relationships.

Indeed, these results provide a more comprehensive picture of the impact of RA on a First Nations individual's activities of daily living. In the next chapter, the quantitative and qualitative findings are integrated and discussed.

6. Integration of Mixed Methods

O’Cathain, Murphy and Nicholl (2010) suggest three methods to integrate data in mixed methods studies: a “mixed methods matrix” (with focus on individual cases for which there is both quantitative and qualitative data); “following a thread” (pursuing one result across both methods); and a “triangulation protocol” (that incorporates the development of a convergence coding matrix and identification of meta-themes across methods). Independent of the approach, the overarching intent is to explore the results for convergence (agreement), complementarity and or dissonance (discrepancy). The six-step triangulation protocol described by Farmer and colleagues (2006) was used to connect the findings of the quantitative and qualitative phases of this study. First, the data was sorted as part of the individual components of the study. Those results were reported independently in Chapters Four and Five.

In this chapter, the data from the quantitative component embedded within the qualitative phase is analyzed using a convergence-coding matrix. While this method was developed by Farmer (2006) to compare results of multiple qualitative approaches, this same approach was chosen to examine the agreement between the MHAQs completed by the 25 participants in the qualitative phase with how they described their activity limitations during the semi-structured interviews (Appendix 16). Every response by the 25 participants to each of the eight questions in the MHAQ was coded as in agreement, partial agreement, silence or dissonance (disagreement). Assessment of the coding results indicated that only 64% of the 200 individual responses were in clear agreement,

16% were in partial agreement, and 16% were dissonant (Table 12). A small percentage (4.5%) was silent where an element of activity limitation was uncovered in the qualitative component, but was absent in the quantitative component.

Table 12. Results of Convergence Coding Matrix

	MHAQ Question								
	Dressing	Bed	Drinking	Walking	Bathing	Bending	Faucets	Vehicles	Total (%)
A*	10	17	19	15	17	16	17	16	127 (63.5%)
PA	3	4	4	5	4	6	3	3	32 (16%)
S	1	1	0	0	3	2	2	0	9 (4.5%)
D	11	3	2	5	1	1	3	6	32 (16%)

*A=Agreement; PA= Partial Agreement; S=Silence; D=Dissonance

The single item in least agreement was “dressing self” where only 40% (10 of 25 MHAQ responses) were in clear agreement with what was described verbally. MHAQ responses reflected the performance^G (not capacity^G) of dressing. In this context of qualification, individuals described the assistance they received (but did not report or account for in the MHAQ); or that they no longer wore clothing with buttons due to difficulty with agility; or that they left their shoelaces permanently tied as was common practice in their community. Hence they had “no difficulty”. From their performance-based responses, there was no indication of any difficulty with capacity. Capacity in this case can be considered a reflection of joint range of motion, strength and agility while performance reflects the achievement of a meaningful activity that may include assistive devices or personal assistance. Arguably, performance should be weighed more heavily than capacity, as this is the true reflection of an individual’s daily living activities. Alternatively, an individual’s care plan may depend to a greater degree on the

assessment of capacity. The risk exists that the underestimation of capacity may result in fewer resources directed at treatment and/or management.

Walking outdoors on flat ground and getting in and out of vehicles independently were the other two items with the least amount of agreement across methods: 60% and 64% respectively. Respondents revealed that walking outdoors was based on an ideal environment and not necessarily on the experience in their home community environment. Getting in and out of a boat was not referenced in the MHAQ yet this form of transportation is the norm in their community. The MHAQ question was limited to “car, bus, train and airplane”. For those living in a remote island community in northern Manitoba, a local bus or train does not exist. Trucks, vans, all-terrain vehicles, ski-doo's and boats are the norm and contribute significantly to the development and maintenance of social roles and activities. They are used for social engagement in a harsh climate; can contribute to the sustenance of a family (e.g. fishing and hunting); and can contribute to the participation in meaningful tasks (e.g. community-held Cultural Days). Referencing these vehicles in the MHAQ would help affected individuals better identify the impact RA has had on their daily lives. Exploring the social significance of these limitations and restrictions (Williams, 1987), can also provide an even deeper understanding of the choices that individuals have made and why.

Silence is the final element of the coding matrix. The ability to care for one's own hair or the ability to participate in traditional tasks was not captured in the MHAQ. Yet, these areas of activity and participation were particularly meaningful, specifically by

gender, to First Nations individuals living with RA. This observation is supported by other authors who have critiqued standardized measures of activity using pre-determined lists as omitting activities meaningful to the individual (Carr & Thompson, 1994; Goodacre et al., 2007; Kaufert, 1983; Ripat, Etcheverry, Cooper, & Tate, 2001). Hair, for example, is a key aspect of human appearance, based on length, style and colour and has been associated with health, virility, sexuality, religion, and military status (Crawford Shearer, 2008; Mirmirani, 2013). Hair has also been associated with social, cultural, and political norms (Batchelor, 2001). Externally, hairstyle can reflect an individual's self-concept, self-identity, and an individual's social, ethnic and class group (Freedman, 1994). In a qualitative study of the meaning of hair loss in 10 North American women while undergoing treatment for breast cancer, Freedman (1994) discovered that hair loss was more traumatic for some women than the actual loss of a breast. Hair loss in women resulting from chemotherapy is a very complicated and very separate matter from this study. It does illustrate, however, the importance of hair in the lives of women and in society. A literature search of Pub Med, CINAHL, Scopus and Embase using search terms "hair" and "Indigenous" or "Aboriginal" or "American Indian" was unsuccessful at locating any publications exploring the importance of hair in Indigenous populations. Anecdotal evidence has suggested, however, that to some North American Indigenous persons, the braiding (or plaiting) of long hair in three strands representing the body, mind and spirit is a particularly meaningful activity. None of the participants in this study, neither male nor female, reflected on the cultural or spiritual aspect of caring for one's own hair. The challenges of hair-care, however, were raised by several young

women. According to Kleinman (1988), a component of meaning in chronic illness is the loss of confidence in one's health and normal bodily functions. The inability to keep up appearances may be for some younger individuals a great personal loss of trust in their own bodies. Caring for one's hair and appearance may represent a ceiling effect in historical hierarchical measures of function. Caring for one's own hair can be likened to the fourth level of Maslow's hierarchy of needs (1943): self-esteem (Carpenito-Moyet, 2003). Conversely, the need for participation in traditional tasks can be linked to Maslow's third level of need: belongingness. Katz's Index of ADL (1963) purported to assess ADL in a developmental hierarchical fashion: bathing, dressing, going to the toilet, transfers, continence, and feeding self. Caring for one's own hair is not listed as part of dressing, but that does not negate its importance. During a time of cultural renewal for Canada's Indigenous Persons, the significance of belonging to a cultural group with its own traditional tasks cannot be overlooked. Whether braiding long hair or participating in fishing or hunting, these tasks may be of particular social significance to many individuals and yet go unexplored.

Also silent in the MHAQ was any reference to mental health. Participants acknowledged that elements of stress and depression related to their condition had an important impact on their lives and yet were not captured in the MHAQ. This is consistent with a recent study that found a clear association between restrictions in social participation and anxiety and depression in addition to symptoms of RA (Benka et al., 2015). Using the Participation Scale, different levels of social participation were tested among more than 200 persons with RA in Eastern Slovakia. The authors found

that individuals who reported more restrictions also tended to report more pain, fatigue and disability regardless of the duration of RA.

Returning to Farmer's triangulation protocol (2006), the next step is the comparison of methods for completeness. The initial quantitative phase of the study proved to be incomplete on its own. The data provided evidence of the significant burden of RA on Indigenous People in Manitoba at a population-based level but was unable to provide any explanation of the individual observations. The subsequent qualitative phase complemented the first by providing personal narratives of the lived experience of RA. The narratives provided personal observations but may not be transferable to a larger population in a different context. The quantitative component embedded within the qualitative phase provided the evidence of the dissonance between what people report in a self-completed measure of activity compared to how they describe their performance of activities of daily living when given the opportunity. In combination, these multiple and mixed methods allowed insight into the complexity of measuring capacity and performance of daily activities in Indigenous Persons living with RA in Manitoba.

The next step in triangulation is researcher comparison. Given the academic progression requirements of doctoral studies, this step was limited to the input of the author's PhD committee members. Their methodological expertise in qualitative, quantitative and mixed methods research, as well as rheumatology and Indigenous health research provided much valuable oversight to the research design and analysis.

The final step of the triangulation protocol is feedback to the stakeholders. Written and oral versions of the findings were shared with participants and other key stakeholders in parallel to the successful completion of the author's written and oral defense of this study. Opportunities were made available for supporting and dissenting opinions from the community and the Assembly of Manitoba Chiefs before wider dissemination of the findings was pursued.

A thorough triangulation protocol as described by Farmer and associates (2006) also includes the identification of meta-themes across methods. This process is more challenging when mixing quantitative with qualitative methods, as compared to multiple qualitative methods. The determination of themes in the quantitative paradigm is limited by the very nature of the research questions to be addressed. Clearly articulated in both research methods, however, is the significance of the impact of living with RA. The meta-theme of significant impact is supported by both the quantitative and qualitative findings. The quantitative data links the measures of self-report with the physical assessment by the health care provider, while the qualitative component provides the personal illness narratives that can account for the significant personal changes resulting in their lives. Both approaches make transparent the impact on the activity and participation of individuals living with RA. These illness narratives will be discussed further in the next chapter along with the implications of the findings on health care policy, delivery, and future health research are explored in the next section.

7. Discussion and Conclusions

Quantitatively, this study confirmed that First Nations persons diagnosed with RA experience a greater level of activity limitations, significantly associated with other disease activity markers (Barnabe et al., 2008, Ferucci et al., 2004, Peschken, 2010). Self-reported activity limitations (MHAQ) were more positively correlated with self-reported pain (pain VAS) than any other disease activity measure. Small but significant correlations were found between the total MHAQ score and the Lansbury Index, affected joint counts, and the Physician's Global Assessment. No differences between cohorts based on ethnicity were found in these variables. A rural background, however, was significantly associated with the total MHAQ score in the First Nations cohort only, a difference that may be explained by the harsh northern climate described by participants in the qualitative phase of the study. Multiple linear regression models confirmed that pain was the greatest single predictor of total MHAQ score. Based on these quantitative analyses alone, it can be concluded that the MHAQ is a valid tool in measuring disability amongst First Nations persons with RA.

In keeping with other studies, there were weak correlations between the self-reported MHAQ scores and the physician's physical findings, confirming various levels of discordance between how patients self-assess their illness and how health care providers assess the disease (Kleinman, 2013; Anderson et al., 2011; Uhlig et al., 2009; Hewlett, 2003). According to Kleinman (1988), *illness* (the human experience of symptoms and suffering), *disease* (the biomedical problem from the health care

practitioner's perspective), and *sickness* (the understanding of a disorder across a population in relation to macrosocial forces such as economics and politics) mean different things to different people. From his perspective, the individual patient is assessing a different concept than the health care provider. Regardless, the general assumption is that both patients and health care providers are trying to make sense of the condition (Williams & Wood, 1986). That is, from either perspective, individuals are trying to understand the parameters of the condition and how best to ameliorate the impact on a broad range of issues, including the social and psychological aspects (Brown & Williams, 1995; Lacaille, White, Backman, & Gignac, 2007; Lempp, Scott, & Kingsley, 2006).

Kleinman (1995) insists that the only valid way to understand illness and treatment is from the patient's and family's worldviews at a local level, where chronic illness and disability take on a social dimension. He defines the "illness narrative" as the personal story told by the patient and his or her family to make sense of the events and the course of suffering. In his book, *The Illness Narratives* (1988), he describes four potential meanings of the illness experience: *symptoms* (and their contextual meaning); *cultural significance* (of the illness to the person); *life world* (the embodiment of the illness in the individual's personal and social life); *explanation and emotion* (the struggle of sick persons and their care providers for explanations of illness and treatment). Multiple illness narratives during the second phase of this study illustrated these various perspectives through the first-hand experiences of First Nations persons living with RA.

In addition, semi-structured interviews immediately following the completion of the MHAQ unmasked possible underreporting in terms of the magnitude of limitations in activities of daily living. The distinction between capacity and performance in the local context provided a deeper understanding of how individuals managed from day to day with existing supports and made behavioral accommodations in response to their progressive impairments. These findings are in keeping with Katz & Morris' (2007) study of 467 Americans with RA. Their telephone survey using the VLA scale found that persons self-imposed limits and added more time rather than using assistance or devices in order to complete daily activities. Possible adaptations have been distinguished in four different ways: selection (that is, avoiding or reducing activities); optimization (individual efforts aimed at optimizing performance); compensation (in response to loss of capacity); and reliance on others (Gignac, Cott & Badley, 2000). In their study of 286 older adults with osteoarthritis and or osteoporosis, Gignac and colleagues found that a wide range of adaptations were used to respond to chronic illness and disability depending on the domain. Compensation processes were used most often in terms of activities of daily living while selection was used less so. In terms of valued discretionary activities, respondents were more likely to report giving up or limiting their participation. Mobility at home and in the community were most likely addressed through compensation (e.g., the use of mobility aids) and optimization (e.g., through exercise), while household activities were addressed through all four strategies (2000). The results of our study differed slightly whereby individuals in our sample described greater reliance on selection strategies in personal care (e.g. avoiding shoes

with laces and or buttons) and increased reliance on others to facilitate participation in discretionary valued activities (traditional tasks). These differences may be explained by a younger cohort of participants or the greater emphasis on traditional tasks in this First Nations cohort. These differences underlie the importance of exploring the different adaptations used in different contexts that individuals may employ while living with chronic conditions.

Individuals in this study, particularly the women, described the unique challenges they faced as parents with RA. This is consistent with the findings of Backman and colleagues (2007) who in their qualitative grounded theory study of 12 women with inflammatory arthritis described the role of mothers. The ability of the women to participate in mothering tasks in their study was impacted by the type and level of support they received offset by personal levels of fatigue and energy. This unpredictable nature of the disease had both positive and negative consequences for the family, similar to the findings described in this study. The difficulty that women have in particular with disclosing their limitations and restrictions to their families has been described previously (Brown & Williams, 1995; Hwang, Kim, & Jun, 2004) as well as the tensions experienced with partners' difficulties in accepting the disease (Lempp, Scott, & Kingsley, 2006; Matheson, Harcourt, & Hewlett, 2010). The impact of RA on self-care in terms of hair care in this study was alluded to previously in Lempp's findings of the influence of RA on individuals' physical identity in the United Kingdom. In their qualitative study of 26 persons living with RA, Lempp and associates reported that more than one third of respondents had changed their physical appearance to accommodate

impairments secondary to RA. One 40 year old woman commented that this practical approach took away some of her femininity (2006). While a similar comment was not made explicitly by any of the participants in this study, the impact of RA on established social roles and self-identify was apparent. In a different qualitative study of 87 individuals with hip or knee osteoarthritis in Ontario, Gignac and associates found that greater pain was associated with less role satisfaction, while activity limitations were not associated with role satisfaction (2008). The authors conclude that the measure of social roles is distinct from measures that focus on activity limitations. These findings are consistent with those of this study, where the MHAQ results were devoid of any meaningful measurement or explanation of the impact of RA on role participation.

Participants in this study frequently reflected on the environmental barriers they faced living in a remote and isolated community. While some issues of geography may be common to non-Indigenous individuals living in northern Canada, issues of poverty “set the scene” (Badley, 2008) differently for Canada’s Indigenous Peoples. A qualitative study of 60 women living with RA in Soweto, South Africa explored similar issues of environmental barriers and facilitators, employment and social inclusion (Schneider, Manabile, & Tikly, 2008). Similarly grounded in the ICF framework, the authors found that low income, lack of sufficient public transport and sparse basic services were features of poverty that exacerbated the negative experiences of living with RA. In this perspective, poverty can be viewed as a key feature in the contextual factors of the ICF mediating the experience of living with a chronic condition. As reported earlier, Beaudin described the impact of personal factors for Indigenous persons as impacting the very

existence of the health condition itself (2010). If poverty is viewed as a contextual influence on the individual's health condition, then the experiences of Indigenous persons living with RA are distinctly different from their non-Indigenous counterparts, regardless of geography.

These different perspectives underscore the challenges in defining a standardized environment, contextual and cultural factors as previously identified by Badley (2008). The relevance of the results to health policy, clinical practice, and future health research in addition to the study limitations are discussed below.

7.1 Implications

The implications of the results of this study can be viewed on three levels: health policy, health care delivery and future health research. These three aspects along with recommendations are deliberated below.

7.1.1 Implications for Health Policy

In the context of this study, the major policy area relevant to First Nations people living with RA in Manitoba pertains to health services and healthy living. For individuals with treaty status living on-reserve, there is a complex web of inter-agency resources subject to three levels of governance: federal, provincial and local Band Council. Matters pertaining to "Indians", according to the *British North America Act*, fall

under the purview of the federal government of Canada. Health, however, falls under provincial jurisdiction. Who funds and delivers health services on-reserve is an on-going dispute between the federal or provincial/territorial governments and is handled differently across the different regions of Canada (Fricke, 1998).

Health Canada's First Nations and Inuit Health Branch (FNIHB) oversees and funds the direct delivery of health services on-reserve in Manitoba, the extent of which varies by the location, size and individual health needs of each community. FNIHB also manages the Non-Insured Health Benefits (NIHB) program described in Section 2.1. This program was not intended to replace provincial health programs, but rather augment what is available. Provincial programs such as Home Care, palliative care and occupational therapy, however, are not universally available on-reserve, while physical therapy is available in some remote communities. FNIHB ensures access to physician and nursing services, in addition to medically necessary equipment and drugs as defined by the NIHB program (Fricke, 1998). As mentioned earlier, where specialists do not travel to the communities, individual patients or clients must travel to large urban centres to access care, for which travel costs are paid for by the NIHB program. However, the delay in access to specialist care can also have long term implications on patient outcomes as previously discussed. Readily accessible specialist services must be supported by relevant policy and funding of such services.

While not a focus of any of the interviews *per se*, access to federally funded medically prescribed medications was an issue raised by a key rheumatologist informant

and two participants. Words such as “frustrating” and “complicated” were used to describe the current authorization process. Recent advances in medical management such as the use of biologics have not been universally accessible to those with treaty status without multiple communications justifying the need for this expensive drug. One informant on a regular biologic, Enbrel[®], suggested that her particular dosage cost approximately \$5000 over a two week period³. This scrutiny by FNIHB may be laudable from the perspective of federal spending constraints, but the lapse in appropriate treatment and the increased time of the specialist clinician are not. It has been stated that accessing these prescription drugs for those on Employment and Income Assistance (EIA) is easier than for those under NIHB. Under EIA processes, all communications are between the pharmacist, clinician and the EIA agent. Under NIHB, all communications are only directed through the insured patient. For the individual recipient unfamiliar with pharmaceutical approval formularies this appears to be a process fraught with challenges from the outset. The powerlessness and associated stress that individuals may encounter in this process may actually increase the physiological pain they already feel as a result of their inflammatory joint disease.

“The powerless in society are at greater risk for stresses they can’t control, supports they can’t mobilize, illnesses of almost all kinds, and death. Our economic and social system places pressures on all of us, but for the powerless the local social system does not (or cannot) deflect the impact or reduce the effect of those pressures on the person....Chronic pain syndromes, originating in the biology of injury and disease, are worsened and prolonged by vicious cycles of misery.”
(Kleinman, 1988, pp 84-85)

³ This cost reflects the recall of one participant. In contrast, an expert informant has suggested that such a \$5000 sample would typically suffice for a three-month period.

Thus the stress created raises a critical cultural safety issue. The discourse of cultural safety developed by Maori nurses in New Zealand suggests that Indigenous Persons are powerless within a health care system grounded in a framework based on colonization (Ramsden, 2005; Ramsden, 1990). Cultural safety acknowledges institutional racism and the nature of a social structure that alienates Indigenous Persons (Polaschek, 1998) while postcolonialism^G theory stresses issues of power differentials (Browne, Smye & Varcoe, 2005). In contrast are the strengths associated with social capital in communities whereby social relationships, formal and informal networks, social norms and values, trust and resources contribute to the health and well-being of its members (Cattell, 2001). The strength of social capital in a First Nations community has been linked to its *bonding* (relations within the community); *bridging* (relations with other communities); and *linkage* (relations with formal institutions) (Mignone & O'Neil, 2005). In this study, participants spoke of the strength they received from their families and community. Policies impacting Indigenous health need to integrate this strong bond within the community and facilitate linkages with relevant institutions. Complex systems that limit access to appropriate medical treatments such as new and effective drug regimens only delay important milestones in aggressive disease management where needed. Medical recommendations for those individuals covered by NIHB should be honored without unnecessary delays similar to EIA recipients. Where policy dictates a requirement of evidence for treatment efficacy, the choice of outcomes measures, however, must be appropriate and relevant to the

context of the individual. If not, there may be an inaccurate estimate of disease activity and associated disablement. Timely access to appropriate treatment options is one of the foremost recommendations of the American College of Rheumatology and should be upheld for both policy as well as clinical practice.

Addressing issues of healthy living in turn requires policies directed more broadly towards food security, education, accessibility, poverty, racism, and equal opportunity. Affordable healthy foods need to be made available across all of Manitoba, as do equitable education programs, anti-racism curriculum and anti-poverty strategies. Environmental barriers, including physical, structural, systemic and attitudinal must be addressed in order to encourage and enhance equal participation for all community members. Whether First Nations Band Councils or the federal government is responsible for accessible housing, air and or water transportation, then pertinent regulations must be enforced. All parties must be proactive in ensuring that the *Canadian Human Rights Act* and the rights of those with disabilities are ensured (Canada Human Rights Commission, 2011). Once healthy policy is accepted as requiring a cross-sector approach, then healthy living may become a reality.

7.1.2 Implications for Clinical Practice

Health care providers are key players in the relevant and meaningful assessment of the impact of chronic illness on the individual person. But if the assessment and the resultant care are to respond to the whole person, then one needs to take “into account

the effects of the person's roles, relationships, and attitudes on his or her experience of chronic illness and how these influence the daily activities they give up or continue in the presence of disablement" (Williams, 1987, p. 97). Comprehending how individuals understand their own condition may lead to greater success in public health programs (MacKay et al., 2015). Monitoring, planning and interventions require consideration of an individual's perspective, personal resources and participation in family and social roles over time (Benka et al., 2015; Davis, Wong, Badley, & Gignac, 2009). Traditional approaches to assessing activity and participation have been critiqued as devoid of the social significance of the activity in a societal context. Health care services and rehabilitation must be based on reciprocal relationships whereby professionals understand the thoughts and language of their patients (Williams, 1986).

Williams (1987) in his seminal UK qualitative study of disablement and RA provides the example of walking. Walking is not merely a physiological act but is steeped in a socio-cultural context. Walking is often done in the companionship of others in the context of a pre-defined societal role, for example, going for a walk with one's partner, grocery shopping for one's self and family, or walking one's children to school. One's role is what links the individual to society: society determines the role and the individual occupies those roles (Williams, 1987). If this act is limited, the role of self takes on new meaning and may require adaptation. As health care providers, it is crucial to understand the social roles of individuals, the relationships with people in related roles, and the value attached to conducting tasks in a particular manner. This deeper

understanding is necessary if health care providers are to help facilitate this transition to a new and adapted role.

Similar to the need for recognizing the societal context of a person's role health empowerment theory emphasizes the integral relationship between persons and their environment (Crawford Shearer, 2008). According to health empowerment theory, a particular focus is placed on purposefully participating in the "process of changing oneself and one's environment, recognizing patterns, and engaging inner resources for well-being" (Ibid.). From a parallel Indigenous worldview, there has been dissatisfaction voiced with a Western health care system that divides the triad of body, mind and spirit from one another and treats them separately (Morse, Young, & Swartz, 1991). A history of distrust grounded in colonialism requires a shared meaning about the vulnerability and power differential inherent in the health care relationship (Ramsden, 2000). When health care providers can effectively integrate these aspects of society, the environment and whole self into health care delivery, then meaningful change and adaptation to chronic illness in First Nations persons is more likely to transpire. How to follow through with such a holistic approach to individuals in a resource-limited environment becomes the challenge.

Holistic care does not necessitate the complete abandonment of disability outcome measures but their overreliance should be avoided. Activity status measures should be used with caution while balancing an individual approach for each patient.

Particularly in situations where health literacy⁴ issues are a concern, they may be of limited value. The use of three simple questions to ascertain inadequate health literacy clinically have been suggested (Chew, Bradley, & Boyko, 2004): “How confident are you filling out medical forms by yourself?”; “How often do you have someone help you read hospital materials?” and “How often do you have problems learning about your medical condition because of difficulty understanding written information?” Using the first two health literacy questions on confidence and assistance in reading medical materials, a recent study uncovered a significant association between low health literacy and functional status measured by HAQ disability index scores (Caplan, Wolfe, Michaud, Quinlanos, & Hirsh, 2014). The authors suggest that health literacy may play an important role in understanding activity and participation in persons with RA. The first question regarding confidence has also been reported as an adequate stand-alone question in the detection of limited health literacy skills (Quinlanos, Hirsh, Bright, & Caplan, 2015; Wallace, Rogers, Roskos, Holiday, & Weiss, 2006). In the qualitative component of this study, the Winnipeg Health Sciences Centre-based cohort (n=12) were asked two similar questions about their personal confidence in filling out medical forms and the frequency with which they needed assistance in reading medical information. In addition to the characteristics of this sub-cohort presented in Table 2 on page 81, the mean number of years of education in this group was 11 years. Of these 12 participants, only one stated that she was not confident in filling out medical forms and

⁴ Health literacy is defined as “the degree to which individuals can obtain, process and understand basic health information and the services needed to make appropriate health decisions” (Nielsen-Bohlman, Panzer & Kindig, 2004 as cited in Quinlanos et al., 2015).

needed help when reading medical information. Interestingly, there was full agreement between all her responses on the self-reported MHAQ and the description of how she completed those same acts during the interview. Her MHAQ score of 0.375 fell well below the mean MHAQ score for her sub-cohort (0.8) as well as the overall MHAQ score of both cohorts together (0.9). In contrast another individual answered she was “quite” confident and never needed help with medical information and yet four of her responses in the MHAQ were discordant with her descriptions provided in the subsequent interview. While this study did not intend to directly explore the rigour of these health literacy-screening questions, reliance on self-reported outcome measures without the assessment of health literacy is incomplete and puts the results of such measures into question.

If self-reported outcome measures of disability are at risk of a lack of reliability and relevance, health care providers are left with the challenge of relying on an open-ended interview, completing the questionnaire through an interviewer or locating an alternative measure. Current outcome measures fail to adequately capture restrictions in participation or societal involvement (Davis, Wong, Badley, & Gignac, 2009). While health care providers are educated in comprehensive history taking, the current focus on evidence-based practice encourages the use of standardized measures. Two such measures that may be useful in this context are the Goal Attainment Scale (Kiresuk & Sherman, 1968; Mastos, Miller, Eliasson, & Imms, 2007) and the Patient Specific Scale (Stratford, Gill, Westaway, & Binkley, 1995). Both scales rely on the identification of meaningful specific activities by the individual patient and are completed by the health

care provider. The Goal Attainment Scale originated in the clinical domain of mental health and is scored on a range from -2 (“baseline”) to 0 (“expected outcome”) to +2 (“much greater than expected outcome”). The Patient Specific Scale was developed by a Canadian physiotherapist for use in rehabilitation and is scored on a Likert scale of 0 (“unable to perform activity”) to 10 (“able to perform activity at the same level as before injury or problem”). Using measures such as these can alert the health care practitioner to the individual concerns raised by each patient. In this manner, treatment and management can be fitted accordingly to each individual circumstance. While some scales may be more relevant to an individual patient, the two scales mentioned above are not currently as widely in use as other well-known measures such as the HAQ and MHAQ and admittedly may have limited research applicability and generalizability. Alternatively, based on the findings of this study, in place of a VAS measuring pain, fatigues and disease activity, a simple numerical rating scale may be preferable.

7.1.3 Implications for Future Health Research

It is acknowledged that outcome measures used for health research purposes must have generalizability and applicability to a wider population. Where self-reported outcome measures like the MHAQ are utilized for clinical research, however, there must be clear instructions to both the respondent and the persons entering the data. In the case of RA where functional status may vary from day to day and from environment to environment, the respondent must be given sufficient and consistent information on

how to complete the survey. The users of the results must be clear if they are seeking details on capacity or performance. For the individuals entering the data, they must have clear and consistent instructions on how to handle data that may be misleading. For instance, if a respondent checks off more than one response or leaves a response blank, the data must be coded appropriately in order to ensure the trustworthiness of the data itself.

In the case of the MHAQ, in addition to increasing its readability by increasing the font and white space on the page, two minor modifications could yield much more relevant responses to the particular population of First Nations people living in Manitoba. The simple addition of “putting up hair” to the question “Can you dress yourself (including tying shoe laces and doing buttons)” would make the question item much more relevant. In a similar fashion, adding “boats, skidoos and ATVs” to “can you get in and out of cars, buses, trains and planes” would make the item much more meaningful to many individuals. The risk of course is that the data will no longer be comparable to previous data gathered or across populations. But without these additional items, the current data likely represents an underestimate of the level of disability. If alternative disability outcome measures are introduced, such as the Goal Attainment Scale (Kiresuk & Sherman, 1968) and the Patient Specific Scale (Stratford, Gill, Westaway, & Binkley, 1995), or the WHO DASII (Üstün, T. B., Kostanjsek, N., Chatterji, S., & Rehm, J. (Eds.) (2010)) then they will need to be validated first, as noted, with a Canadian Indigenous population.

An additional recommendation for future health research includes the exploration of the utility of disability outcome measures from the perspective of health care providers working with Indigenous individuals with RA and other chronic illnesses. If outcome measures are found to have limited relevance in the clinical setting, then reasons for this need to be uncovered and alternatives explored. The perspective of non-Indigenous individuals with RA in terms of their own interpretation of self-reported disability outcome measures should also be pursued.

7.2 Research Questions Re-visited

The overall research objective was to determine whether or not the MHAQ in its current form is an appropriate tool to measure the impact of RA on the activity and participation of First Nations People. To achieve this objective, seven research questions were posed. The first two had to do with completion of the MHAQ itself: what were the completion rates and was there a pattern in missing responses. The quantitative data analysis confirmed a completion rate of 91.3% in the First Nations cohort (compared to 94.6% in the Caucasian cohort). Based on the second phase of this study, completion rates were closer to 80%. This figure is reduced further to 65% when one considers the rigour of completion demonstrated in the convergence-coding matrix. While there was no discernable pattern of missing responses in the eight questions specific to the MHAQ, respondent fatigue may have contributed to missing responses in the additional questions below.

The third research question pertained to the concurrent validity of the MHAQ when correlated with other markers of disease activity. This was addressed in the quantitative phase and was indeed positively supported. The fourth and fifth research questions addressed the personal interpretation and meaningfulness of the MHAQ items. The qualitative phase of the study confirmed that the interpretation of the MHAQ was inconsistent across the sample and its relevance varied between individuals. For individuals living in remote northern communities, the items were not universally relevant.

In response to the sixth research question, elements of activity with personal meaning and relevance that were missing in the MHAQ were identified in the qualitative interviews. Taking care of one's hair and engagement in traditional tasks were exemplars of such activities. Social support networks such as spouses and children were effective facilitators of engagement, while the environment could create barriers for many individuals.

The final research question focused on the optimization of current care on both a policy and service delivery level. Issues of timely access to appropriate care were raised in the literature review and the discussion on health policy and health care implications. Recommendations have been made for the utilization of relevant and meaningful outcome measures in order to support equitable care based on true not perceived need. Effective partnerships and meaningful networks of care can move this pursuit forward.

7.3 Study Limitations

This study has focused on the relevance of the MHAQ and its use with First Nations persons living in Manitoba over the age of 18 with a diagnosis of Rheumatoid Arthritis or Juvenile Rheumatoid Arthritis. Although restricting this study to this unique population is one of its strengths, it is also one of its limitations. This study did not explore how non-Indigenous Persons interpret the MHAQ or its relevance to their own context of living with RA. The findings may not be generalizable to the non-Indigenous population residing in Manitoba or elsewhere. Nor should the findings be transferred to other Indigenous populations living elsewhere in the province or outside Manitoba. Indigenous populations as previously defined are heterogeneous groups and the experiences of one particular group should not be understood as the universal truth for all. Similar experiences may exist across various populations, but assumptions should be avoided.

A second limitation of the study was the absence of input from health care providers who interpret and use the information gathered in the MHAQ for individual care planning. It is unknown if and how care is modified based on the results of the MHAQ or what if any meaning it has for the health care provider.

Limitations specific to the database used in the quantitative phase of this study were presented in Section 3.1. To summarize, these weaknesses pertained to an absence in the database of details regarding geography, treaty status, eligibility for Non-

Insured Health Benefits, proficiency of English, the use of an interpreter, and the prescribed treatments. In addition to the absence of these variables, there was also limited information on how to handle missing data as listed in Table 1. It is not known what impact the missing data would have had on the analysis of the data; nor is it known precisely why some elements of the data were missing or incomplete. Certain assumptions were made based on linking the unknown variables to other known variables based on the expertise of the clinician familiar with the database. Elements of uncertainty persisted nevertheless and were described in Section 3.2 on Missing Data. In addition, it is unclear how persons selected their own ethnicity from a list of options, where the labels “First Nations”, “Métis”, and “White” were undefined. A false coding of ethnicity could have implications on the quantitative data analysis but given the large sample size, the author remains confident in the results.

In terms of the limitations of the qualitative phase of the study, the impact of the clinical setting on the interviews was first described in Section 3.3 Interview Settings. This was more noticeable at the Winnipeg Health Sciences Centre than in the St. Theresa Point nursing station. Interviews were subject to overhead announcements, the pressure of having to move a vehicle or get an X-ray taken before the lunch break for example. It is possible that the researcher found these external factors more disruptive than the participants. This was addressed in part by locating a room removed from the clinical area. Another limitation was the absence of a non-Indigenous perspective. This deficiency precluded any sort of comparison across population groups. Had a similar convergence coding matrix been uncovered with a non-Indigenous population, issues of

geography, the environment or other unanticipated challenges may have come to the fore. Regardless of the possibility of similar findings in non-Indigenous individuals from other remote areas, however, the fact that this experience is shared by entire communities representing thousands of persons cannot be minimized. Coupled with increased prevalence rates of RA, the severity of the disease and racism towards Indigenous Peoples in Manitoba and across Canada, these narratives tell a unique story. In terms of diversity within the qualitative sample, the majority of the participants were female consistent with the epidemiology of the disease. Only three of the 25 participants overall were currently living in Winnipeg. The impact of urban-based living was therefore likely under-explored. A larger qualitative sample size may have provided more variance in the responses.

The content analysis of the qualitative phase used preconceived codes specific to the MHAQ and the ICF. While providing a useful framework based on the literature, Thorne (2008, p. 167) advises that this may situate the analysis at risk of “premature closure”. It is believed that this was countered by the subsequent thematic analysis.

A final limitation worth noting was the potential for researcher bias in the interpretation of this study. The researcher’s background as a physiotherapist and one who has previously worked in the neighbouring communities could have biased the interviews and their interpretation. The researcher’s clinical background was often difficult to separate from the researcher role, as individual participants described the hardships and challenges they were facing in their home community. Where an element

seemed amenable to rehabilitation, aids or adaptations, recommendations were left with either the participant or the attending rheumatologist for follow up. By being cognizant of this potential for competing roles, it is hoped that the interaction remained true to its original intent, that is, one of exploration into the lived experience.

7.4 Researcher Reflections

The potential for researcher bias identified above is based on the background of the researcher and the experiences she encountered while working in the region 15 years earlier. Much has changed in this time period, which was not expected. This was evident from the outset where the air in the local airport no longer hung heavy with the scent of wood smoke and oil. The proficient and articulate use of the English language was also not anticipated. According to the researcher's prior clinical experience, approximately half of the population older than 50 then would have benefited from an English language interpreter but this was no longer the case. The loss of the Oji-Cree language is perhaps the more pressing concern. Other signs of a cultural shift appeared in the manner of dress of older women. Where 15 years ago, many older women wore multiple layers of clothing including covering their heads with a scarf, today older women were wearing shorts and T-shirts. The availability of running water and the prolific use of cell phones were further signs of change.

What had not changed was the on-going evidence of poverty and under-funded infrastructure in a harsh and remote environment. Dusty roads pockmarked with potholes and wooden docks in disrepair in an island community dependent on water

transportation make accessibility challenging even for the able-bodied. Discarded appliances and vehicles in household yards put children at risk of injury and of polluting the watershed. Also unchanged, however, were the signs of on-going resilience in the community. The abundance of children's toys, the great care that individuals took in their appearance and private economic initiatives such as selling ice cream from the front door of a home were all signs of living into the future. The profusion of laughter and humour also remained untouched, an element of Island Lake familiar to all who have lived and worked in this region.

The author is extremely grateful to have been given the opportunity to return to Island Lake and to share in the stories and get a glimpse of the on-going experiences of the local residents. Canadians have gained much from the realities revealed in the Royal Commission on Aboriginal Peoples in 1996 and the 2015 report of the Truth and Reconciliation Commission. But to visit the communities and hear the experiences first-hand, was invaluable for a first generation Canadian trying to gain an even small understanding of the daily challenges faced by Indigenous Persons in this country and the strength with which they overcome them.

7.5 Conclusions

This study confirmed previous reports of significant disability experienced by Indigenous persons living with RA. Multiple and mixed methods uncovered the extent of underreporting of capacity when using a self-reported index of activity. It is critical to

consider activity and participation in the context of the individual lived experience. This study confirmed that “[t]heories and explanatory models that define health and illness are culturally conditioned and framed within culturally determined belief systems” (Freedman, 1994, p. 340). For effective management of chronic illness, the environmental, social and cultural aspects of disability must be addressed. Where clinical health research hinges on the accurate measurement of capacity as well as performance then outcome measures such as the MHAQ cannot be relied upon in isolation. If the goal is to estimate the overall burden of disease, then the different types of accommodation used in activities and participation must also be considered (Katz & Morris, 2007). While the quantitative results in this study were silent on matters pertaining to participation and/or the fulfillment of roles in the family or society, the qualitative results were able to explore these complex topics. The qualitative portion of this study discovered that many individuals overestimated their capacity but not their performance: individuals had modified their behavior or environment such that difficult tasks were no longer relevant. In other words, MHAQ results were in fact an underestimation of the degree of activity limitation and failed to address participation at all.

Finally, the assessment of disability requires an integrated approach, whereby abnormalities in body function and structure, as well as activity limitations and participation restrictions can be addressed within the personal context of environmental, personal and attitudinal barriers and facilitators. Activities that are obligatory, committed or discretionary must be considered and dealt with

appropriately. Prior research using this database has already provided a very valuable contribution to the literature in regards to understanding RA in Indigenous populations. Through this work, it is hoped that the complexity of disablement and the importance of meaningful engagement of the individuals affected by RA have been highlighted and through dissemination of the results, will begin to fill a gap in the current evidence.

Significance of the Study

This study confirmed the disproportionate impact of RA on a First Nations population. A convergence coding matrix provided a novel approach to integrate the findings of a quantitative and qualitative mixed methods study. Concurrent validity of the MHAQ with Indigenous Persons with RA was supported but not convergent validity, where MHAQ scores were an underestimate of disability. The results support the need for an integrated approach to the assessment of activity and participation.

References

- Aday, L. A., & Cornelius, L. J. (2006). Defining and clarifying the survey variables. *Designing and conducting health surveys* (pp. 48-80). San Francisco, CA, USA: Jossey-Bass.
- Aletaha, D., Neogi, T., Silman, A. J., Funovits, J., Felson, D. T., Bingham, C. O., 3rd, . . . Hawker, G. (2010a). 2010 rheumatoid arthritis classification criteria: An American College of Rheumatology/European league against rheumatism collaborative initiative. *Arthritis and Rheumatism*, *62*(9), 2569-2581. doi:10.1002/art.27584
- Aletaha, D., Neogi, T., Silman, A. J., Funovits, J., Felson, D. T., Bingham, C. O., 3rd, . . . Hawker, G. (2010b). 2010 rheumatoid arthritis classification criteria: An American college of rheumatology/European league against rheumatism collaborative initiative. *Annals of the Rheumatic Diseases*, *69*(9), 1580-1588. doi:10.1136/ard.2010.138461
- Alford, V. M., Remedios, L. J., Webb, G. R., & Ewen, S. (2013). The use of the international classification of functioning, disability and health (ICF) in Indigenous healthcare: A systematic literature review. *International Journal for Equity in Health*, *12*, 32-9276-12-32. doi:10.1186/1475-9276-12-32; 10.1186/1475-9276-12-32
- American College of Rheumatology Ad Hoc Committee on Clinical Guidelines. (1996). Guidelines for the management of rheumatoid arthritis. American college of rheumatology ad hoc committee on clinical guidelines. *Arthritis and Rheumatism*, *39*(5), 713-722.
- American College of Rheumatology Subcommittee on Rheumatoid Arthritis Guidelines. (2002). Guidelines for the management of rheumatoid arthritis: 2002 update. *Arthritis and Rheumatism*, *46*(2), 328-346.
- Amjadi, S. S., Maranian, P. M., Paulus, H. E., Kaplan, R. M., Ranganath, V. K., Furst, D. E., Western Consortium of Practicing Rheumatologists. (2009). Validating and assessing the sensitivity of the health assessment questionnaire-disability index-derived short form-6D in patients with early aggressive rheumatoid arthritis. *The Journal of Rheumatology*, *36*(6), 1150-1157. doi:10.3899/jrheum.080959
- Anderson, D. L. (2001). Development of an instrument to measure pain in rheumatoid arthritis: Rheumatoid arthritis pain scale (RAPS). *Arthritis and Rheumatism*, *45*(4), 317-323. doi:2-X
- Anderson, J. K., Zimmerman, L., Caplan, L., & Michaud, K. (2011). Measures of rheumatoid arthritis disease activity: Patient (PtGA) and provider (PrGA) global assessment of disease activity, disease activity score (DAS) and disease activity score with 28-joint counts (DAS28), simplified disease activity index (SDAI), clinical disease activity index (CDAI), patient activity score (PAS) and patient activity score-II (PASII), routine assessment of patient index data (RAPID), rheumatoid arthritis disease activity index (RADAI) and rheumatoid arthritis disease activity index-5 (RADAI-5), chronic arthritis systemic index (CASI), patient-based disease activity score with ESR (PDAS1) and patient-based disease activity score without

- ESR (PDAS2), and mean overall index for rheumatoid arthritis (MOI-RA). *Arthritis Care & Research*, 63(S11), S14-S36. doi:10.1002/acr.20621
- Angel, R. J. (2006). Narrative and the fundamental limitations of quantification in crosscultural research. *Medical Care. Measurement in a Multi-Ethnic Society*, 44(11) (Suppl 3), S31-S33. doi:10.1097/01.mlr.0000245428.03255.cf
- Armstrong, M. J., & Fitzgerald, M. H. (1996). Culture and disability studies: An anthropological perspective. *Rehabilitation Education*, 10(4), 247-304.
- Asmundson, G. J. G., & Wright, K. D. (2004). Biopsychosocial approaches to pain. In T. Hadjistavropoulos, & K. D. Craig (Eds.), *Pain: Psychological perspectives* (pp. 35-57). Mahwah, NJ, USA: Lawrence Erlbaum. Retrieved from www.doadmc.pk
- Atkins, C., Reuffel, L., Roddy, J., Platts, M., Robinson, H., & Ward, R. (1988). Rheumatic disease in the Nuu-chah-nulth Native Indians of the Pacific Northwest. *The Journal of Rheumatology*, 15(4), 684-690.
- Backman, C. L., Smith Ldel, F., Smith, S., Montie, P. L., & Suto, M. (2007). Experiences of mothers living with inflammatory arthritis. *Arthritis and Rheumatism*, 57(3), 381-388.
- Badley, E. M. (2008). Enhancing the conceptual clarity of the activity and participation components of the international classification of functioning, disability, and health. *Social Science & Medicine*, 66(11), 2335-2345.
- Bannon, W. M. (2013). *The 7 steps of data analysis: A manual for conducting a quantitative research study*. Brooklyn, N.Y: Stats Whisperer Press.
- Barnabe, C., Elias, B., Bartlett, J., Roos, L., & Peschken, C. (2008). Arthritis in Aboriginal Manitobans: Evidence for a high burden of disease. *The Journal of Rheumatology*, 35(6), 1145-1150.
- Batchelor, D. (2001). Hair and cancer chemotherapy: Consequences and nursing care -- a literature study. *European Journal of Cancer Care*, 10(3), 147-163.
- Beasley, R. P., Willkens, R. F., & Bennett, P. H. (1973). High prevalence of rheumatoid arthritis in Yakima Indians. *Arthritis and Rheumatism*, 16(6), 743-748.
- Beaudin, P. G. (2010). *A contemporary socio-cultural exploration of health and healing: Perspectives from members of the Oneida nation of the Thames (onyota'a:Ka)*. (Unpublished Doctor of Philosophy). University of Western Ontario, London, Ontario, Canada.
- Bell, M. J., Tavares, R., Guillemin, F., Bykerk, V. P., Tugwell, P., & Wells, G. A. (2010). Development of a self-administered early inflammatory arthritis detection tool. *BMC Musculoskeletal Disorders*, 11, 50. doi:10.1186/1471-2474-11-50

- Bellamy, N. (1989). Critical review of clinical assessment techniques for rheumatoid arthritis trials: New developments. *Scandinavian Journal of Rheumatology. Supplement, 80*, 3-16.
- Benka, J., Nagyova, I., Rosenberger, J., Macejova, Z., Lazurova, I., van der Klink, J. L., van Dijk, J. P. (2015). Social participation in early and established rheumatoid arthritis patients. *Disability and Rehabilitation, 1-8.*
- Bennett, D. A. (2001). How can I deal with missing data in my study? *Australian and New Zealand Journal of Public Health, 25*(5), 464-469.
- Bergner, M., Bobbitt, R. A., Pollard, W. E., Martin, D. P., & Gilson, B. S. (1976). The sickness impact profile: Validation of a health status measure. *Medical Care, 14*(1), 57-67.
- Bickenbach, J. E., Chatterji, S., Badley, E. M., & Üstün, T. B. (1999). Models of disablement, universalism and the international classification of impairments, disabilities and handicaps. *Social Science & Medicine (1982), 48*(9), 1173-1187.
- Bowling, A. (1997). *Measuring health: A review of quality of life measurement scales* (2nd ed.). Philadelphia, USA: Open University Press.
- Boyd, T. A., Bonner, A., Thorne, C., Boire, G., Hitchon, C., Haraoui, B. P., Pope, J. E. (2013). The relationship between function and disease activity as measured by the HAQ and DAS28 varies over time and by rheumatoid factor status in early inflammatory arthritis (EIA). results from the CATCH cohort. *The Open Rheumatology Journal, 7*, 58-63.
- Boyer, G. S., Templin, D. W., & Lanier, A. P. (1991). Rheumatic diseases in Alaskan Indians of the southeast coast: High prevalence of rheumatoid arthritis and systemic lupus erythematosus. *The Journal of Rheumatology, 18*(10), 1477-1484.
- Brown, S., & Williams, A. (1995). Women's experiences of rheumatoid arthritis. *Journal of Advanced Nursing, 21*(4), 695-701.
- Browne, A. J., Smye, V. L., & Varcoe, C. (2005). The relevance of postcolonial theoretical perspectives to research in Aboriginal health. *The Canadian Journal of Nursing Research = Revue Canadienne De Recherche En Sciences Infirmieres, 37*(4), 16-37.
- Bruce, B., & Fries, J. F. (2003). The Stanford health assessment questionnaire: A review of its history, issues, progress, and documentation. *The Journal of Rheumatology, 30*(1), 167-178.
- Bryman, A. (2006). Integrating quantitative and qualitative research: How is it done? *Qualitative Research, 6*(1), 97--113.
- Bury, M. (1991). The sociology of chronic illness: A review of research and prospects. *Sociology of Health & Illness, 13*(4), 451-468.
- Bykerk, V. P., Akhavan, P., Hazlewood, G. S., Schieir, O., Dooley, A., Haraoui, B., Bombardier, C. (2012). Canadian rheumatology association recommendations for pharmacological

- management of rheumatoid arthritis with traditional and biologic disease-modifying antirheumatic drugs. *Journal of Rheumatology*, 39(8), 1559-1582.
- Bykerk, V. P., Shadick, N., Frits, M., Bingham, C. O., 3rd, Jeffery, I., Iannaccone, C., Solomon, D. H. (2014). Flares in rheumatoid arthritis: Frequency and management. A report from the BRASS registry. *The Journal of Rheumatology*, 41(2), 227-234.
- Callahan, L. F., Mielenz, T., Freburger, J., Shreffler, J., Hootman, J., Brady, T., Schwartz, T. (2008). A randomized controlled trial of the people with arthritis can exercise program: Symptoms, function, physical activity, and psychosocial outcomes. *Arthritis and Rheumatism*, 59(1), 92-101.
- Calvo, F. A., Calvo, A., Berrocal, A., Pevez, C., Romero, F., Vega, E., Alarcon, G. S. (1999). Self-administered joint counts in rheumatoid arthritis: Comparison with standard joint counts. *The Journal of Rheumatology*, 26(3), 536-539.
- Campbell, S. K. (2006). Are models of disability useful in real cases? Pediatric case examples realized in research, clinical practice, and education. *Physical Therapy*, 86(6), 881-887.
- Canada Human Rights Commission (2011) *Human Rights Handbook for First Nations. Rights-Responsibility-Respect*. Cat. No. HR4-10/2011E. Ottawa: Minister of Public Works and Government Services
- Caplan, L., Wolfe, F., Michaud, K., Quinzanos, I., & Hirsh, J. M. (2014). Strong association of health literacy with functional status among rheumatoid arthritis patients: A cross-sectional study. *Arthritis Care & Research*, 66(4), 508-514.
- Carpenito-Moyet, L. (2003). Maslow's hierarchy of needs -- revisited. *Nursing Forum*, 38(2), 3-4.
- Carr, A., Hewlett, S., Hughes, R., Mitchell, H., Ryan, S., Carr, M., & Kirwan, J. (2003). Rheumatology outcomes: The patient's perspective. *The Journal of Rheumatology*, 30(4), 880-883.
- Carr, A. J., & Thompson, P. W. (1994). Towards a measure of patient-perceived handicap in rheumatoid arthritis. *British Journal of Rheumatology*, 33(4), 378-382.
- Carr, A. J., Thompson, P. W., & Kirwan, J. R. (1996). Quality of life measures. *British Journal of Rheumatology*, 35(3), 275-281.
- Carter, J. D., Lodhi, A. B., Nagda, S. R., Ricca, L., Ward, C., Traina, E., Vasey, F. B. (2007). Determining rheumatologists' accuracy at assessing functional disability in rheumatoid arthritis patients using the health assessment questionnaire-disability index. *The Journal of Rheumatology*, 34(5), 958-963.
- Cattell, V. (2001). Poor people, poor places, and poor health: The mediating role of social networks and social capital. *Social Science & Medicine (1982)*, 52(10), 1501-1516.

- Chambers, L. W., Macdonald, L. A., Tugwell, P., Buchanan, W. W., & Kraag, G. (1982). The McMaster health index questionnaire as a measure of quality of life for patients with rheumatoid disease. *The Journal of Rheumatology*, *9*(5), 780-784.
- Chambers, L. W., Sackett, D. L., Goldsmith, C. H., Macpherson, A. S., & McAuley, R. G. (1976). Development and application of an index of social function. *Health Services Research*, *11*(4), 430-441.
- Chew, L. D., Bradley, K. A., & Boyko, E. J. (2004). Brief questions to identify patients with inadequate health literacy. *Family Medicine*, *36*(8), 588-594.
- Cioffi, G., Viapiana, O., Ognibeni, F., Dalbeni, A., Giollo, A., Adami, S., . . . Rossini, M. (2015). Prevalence and factors related to inappropriately high left ventricular mass in patients with rheumatoid arthritis without overt cardiac disease. *Journal of Hypertension*, *33*(10), 2141-2149.
- Coenen, M., Cieza, A., Stamm, T. A., Amann, E., Kollerits, B., & Stucki, G. (2006). Validation of the international classification of functioning, disability and health (ICF) core set for rheumatoid arthritis from the patient perspective using focus groups. *Arthritis Research & Therapy*, *8*(4), R84.
- Community Futures Kitayan. (n.d.). St. Theresa Point First Nation. Retrieved from <http://kitayan.ca/?p=157>
- Conn, V. S., Hafdahl, A. R., Minor, M. A., & Nielsen, P. J. (2008). Physical activity interventions among adults with arthritis: Meta-analysis of outcomes. *Seminars in Arthritis and Rheumatism*, *37*(5), 307-316. doi:10.1016/j.semarthrit.2007.07.006
- Crawford Shearer, N. B. (2008). Hair, hands, and oxygen tanks: Embodiment and health empowerment in homebound older women. *Visions: The Journal of Rogerian Nursing Science*, *15*(1), 18-27.
- Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches*. (3rd ed.). Thousand Oaks, CA, USA: Sage.
- Creswell, J. W., Fetters, M. D., & Ivankova, N. V. (2004). Designing a mixed methods study in primary care. *Annals of Family Medicine*, *2*(1), 7-12.
- Davis, A. M., Wong, R., Badley, E. M., & Gignac, M. A. (2009). There's more to life than everyday function: The challenge of measuring social role participation in ankylosing spondylitis. *Nature Clinical Practice. Rheumatology*, *5*(1), 46-51.
- de Jong, Z., van der Heijde, D., McKenna, S. P., & Whalley, D. (1997). The reliability and construct validity of the RAQoL: A rheumatoid arthritis-specific quality of life instrument. *British Journal of Rheumatology*, *36*(8), 878-883.

- Deane, K. D., & El-Gabalawy, H. (2014a). Pathogenesis and prevention of rheumatic disease: Focus on preclinical RA and SLE. *Nature Reviews. Rheumatology*, *10*(4), 212-228.
- Deane, K. D., & El-Gabalawy, H. (2014b). Pathogenesis and prevention of rheumatic disease: Focus on preclinical RA and SLE. *Nature Reviews. Rheumatology*, *10*(4), 212-228.
- Deane, K. D., Norris, J. M., & Holers, V. M. (2010). Preclinical rheumatoid arthritis: Identification, evaluation, and future directions for investigation. *Rheumatic Diseases Clinics of North America*, *36*(2), 213-241.
- Deering, K. N., Lix, L. M., Bruce, S., & Young, T. K. (2009). Chronic diseases and risk factors in Canada's northern populations: Longitudinal and geographic comparisons. *Canadian Journal of Public Health. Revue Canadienne De Sante Publique*, *100*(1), 14-17.
- Del Puente, A., Knowler, W. C., Pettitt, D. J., & Bennett, P. H. (1989). High incidence and prevalence of rheumatoid arthritis in pima Indians. *American Journal of Epidemiology*, *129*(6), 1170-1178.
- Duffy, M. E. (1987). Methodological triangulation: A vehicle for merging quantitative and qualitative research methods. *Image: The Journal of Nursing Scholarship*, *19*(3), 130-133.
- Dye, J. F., Schatz, I. M., Rosenberg, B. A., & Coleman, S. T. (2000). Constant comparison method: A kaleidoscope of data. *The Qualitative Report*, *4*(1/2) Retrieved from <http://www.nova.edu/ssss/QR/QR3-4/dye.html>
- El Meidany, Y. M., El Gaafary, M. M., & Ahmed, I. (2003). Cross-cultural adaptation and validation of an Arabic health assessment questionnaire for use in rheumatoid arthritis patients. *Joint, Bone, Spine : Revue Du Rhumatisme*, *70*(3), 195-202.
- El-Gabalawy, H. (2005). Common denominators of inflammatory joint diseases. *The Journal of Rheumatology. Supplement*, *72*, 3-6.
- El-Gabalawy, H. S., Robinson, D. B., Smolik, I., Hart, D., Elias, B., Wong, K., Fritzler, M. J. (2012). Familial clustering of the serum cytokine profile in the relatives of rheumatoid arthritis patients. *Arthritis & Rheumatism*, *64*(6), 1720-1729.
- Elliott, B. A., Johnson, K. M., Leff, R. D., & Day, J. J. (2000). Arthritis in Indian country: Determining the prevalence and effects. *Ethnicity & Disease*, *10*(2), 224-231.
- Emery, P., Breedveld, F. C., Dougados, M., Kalden, J. R., Schiff, M. H., & Smolen, J. S. (2002). Early referral recommendation for newly diagnosed rheumatoid arthritis: Evidence based development of a clinical guide. *Annals of the Rheumatic Diseases*, *61*(4), 290-297.
- Escalante, A., Galarza-Delgado, D., Beardmore, T. D., Baethge, B. A., Esquivel-Valerio, J., Marines, A. L., & Mingrone, M. (1996). Cross-cultural adaptation of a brief outcome questionnaire for Spanish-speaking arthritis patients. *Arthritis and Rheumatism*, *39*(1), 93-100.

- Escalante, A., Haas, R. W., & del Rincón, I. (2004). Measurement of global functional performance in patients with rheumatoid arthritis using rheumatology function tests. *Arthritis Research & Therapy*, 6(4), R315-25. doi:10.1186/ar1188
- Farmer, T., Robinson, K., Elliott, S. J., & Eyles, J. (2006). Developing and implementing a triangulation protocol for qualitative health research. *Qualitative Health Research*, 16(3), 377-394. doi:16/3/377 [pii]
- Faul, F., Erdfelder, E., Lang, A. -, & Buchner, A. (2007). G*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods*, 39, 175-191.
- Felson, D. T., Anderson, J. J., Boers, M., Bombardier, C., Chernoff, M., Fried, B., Lightfoot, R. (1993). The American college of rheumatology preliminary core set of disease activity measures for rheumatoid arthritis clinical trials. the committee on outcome measures in rheumatoid arthritis clinical trials. *Arthritis and Rheumatism*, 36(6), 729-740.
- Ferraz, M. B., Quaresma, M. R., Aquino, L. R., Atra, E., Tugwell, P., & Goldsmith, C. H. (1990). Reliability of pain scales in the assessment of literate and illiterate patients with rheumatoid arthritis. *The Journal of Rheumatology*, 17(8), 1022-1024.
- Ferucci, E. D., Templin, D. W., & Lanier, A. P. (2004). Rheumatoid arthritis in American Indians and alaska Natives: A review of the literature. *Seminars in Arthritis and Rheumatism*, 34(4), 662-667.
- Field, A. (2006). *Discovering statistics using SPSS* (2nd ed.). Thousand Oaks, CA: Sage Publications.
- Fillenbaum, G. G., & Smyer, M. A. (1981). The development, validity, and reliability of the OARS multidimensional functional assessment questionnaire. *Journal of Gerontology*, 36(4), 428-434.
- Finch, E., Brooks, D., Stratford, P., & Mayo, N. (2002). *Physical rehabilitation outcome measures: A guide to enhanced clinical decision-making* (2nd ed.). Hamilton, ON: Canadian Physiotherapy Association.
- Finkelstein, V. (1993). The commonality of disability. In J. Swain, V. Finkelstein, S. French & M. Oliver (Eds.), *Disabling barriers, enabling environments* (). Thousand Oaks, CA, USA: Sage.
- Finkelstein, V. (1989). Planning services together with disabled people: The importance of a common language. *World Health Statistics Quarterly.Rapport Trimestriel De Statistiques Sanitaires Mondiales*, 42(3), 177-179.
- Firestein, G. S. (2003). Evolving concepts of rheumatoid arthritis. *Nature*, 423(6937), 356-361. doi:10.1038/nature01661

- First Nations and Inuit Health Branch Health Canada. (2011). *Non-insured health benefits program annual report 2009/2010*. Ottawa, Canada: Health Canada. Retrieved from http://www.hc-sc.gc.ca/fniah-spnia/alt_formats/pdf/pubs/nihb-ssna/2010_rpt/2010_rpt-eng.pdf
- Fitzpatrick, R., Ziebland, S., Jenkinson, C., Mowat, A., & Mowat, A. (1993). A comparison of the sensitivity to change of several health status instruments in rheumatoid arthritis. *The Journal of Rheumatology*, 20(3), 429-436.
- Forestier, R., Andre-Vert, J., Guillez, P., Coudeyre, E., Lefevre-Colau, M. M., Combe, B., & Mayoux-Benhamou, M. A. (2009). Non-drug treatment (excluding surgery) in rheumatoid arthritis: Clinical practice guidelines. *Joint, Bone, Spine : Revue Du Rhumatisme*, 76(6), 691-698.
- Fransen, J., & Stucki, G. (1998). Current use of health status instruments in randomised controlled trials on patients with rheumatoid arthritis. *Disease Management & Health Outcomes*, 3(6), 271-277.
- Frayne, S. M., Burns, R. B., Hardt, E. J., Rosen, A. K., & Moskowitz, M. A. (1996). The exclusion of non-English-speaking persons from research. *Journal of General Internal Medicine*, 11(1), 39-43.
- Freedman, T. G. (1994). Social and cultural dimensions of hair loss in women treated for breast cancer. *Cancer Nursing*, 17(4), 334-341.
- Fricke, M. (1998). *First nations people with disabilities: An analysis of service delivery in Manitoba* (MSc).
- Fricke, M. (2015). *Ka-wachi-wa-pinaywin (coldness in the bones): the application of a Canadian first nations disablement framework to rheumatoid arthritis*. *Physiotherapy Practice*, 5(2), 28-30.
- Fries, J. F., Spitz, P., Kraines, R. G., & Holman, H. R. (1980). Measurement of patient outcome in arthritis. *Arthritis and Rheumatism*, 23(2), 137-145.
- Fries, J. F., Spitz, P. W., & Young, D. Y. (1982). The dimensions of health outcomes: The health assessment questionnaire, disability and pain scales. *The Journal of Rheumatology*, 9(5), 789-793.
- Frytak, J. R. (2000). Assessment of quality of life in older adults. In R. L. Kane, & R. A. Kane (Eds.), *Assessing older persons: Measures, meaning, and practical applications* (pp. 200-235). New York, USA: Oxford University Press.
- Gaston-Johansson, F., Albert, M., Fagan, E., & Zimmerman, L. (1990). Similarities in pain descriptions of four different ethnic-culture groups. *Journal of Pain and Symptom Management*, 5(2), 94-100.

- Getty, G. A. (2010). The journey between western and Indigenous research paradigms. *Journal of Transcultural Nursing: Official Journal of the Transcultural Nursing Society / Transcultural Nursing Society*, 21(1), 5-14.
- Gignac, M. A. M., Cott, C., & Badley, E. M. (2000). Adaptation to chronic illness and disability and its relationship to perceptions of independence and dependence. *Journal of Gerontology: Psychological Sciences* 55B(6), P362-P372.
- Gignac, M. A., Backman, C. L., Davis, A. M., LaCaille, D., Mattison, C. A., Montie, P. & Badley, E. M. (2008). Understanding social role participation: What matters to people with arthritis? *Journal of Rheumatology* 35, 1655-1663.
- Gignac, M. A. M., Cao, X., McAlpine, J., & Badley, E. M. (2011). Measures of disability: Arthritis impact measurement scales 2 (AIMS2), arthritis impact measurement scales 2-short form (AIMS2-SF), the organization for economic cooperation and development (OECD) long-term disability (LTD) questionnaire, EQ-5D, world health organization disability assessment schedule II (WHODASII), late-life function and disability instrument (LLFDI), and late-life function and disability instrument-abbreviated version (LLFDI-abbreviated). *Arthritis Care & Research*, 63(S11), S308-S324.
- Gonzalez, A., Maradit Kremers, H., Crowson, C. S., Nicola, P. J., Davis, J. M., 3rd, Therneau, T. M., Gabriel, S. E. (2007). The widening mortality gap between rheumatoid arthritis patients and the general population. *Arthritis and Rheumatism*, 56(11), 3583-3587.
- Gonzalez, V. M., Stewart, A., Ritter, P. L., & Lorig, K. (1995). Translation and validation of arthritis outcome measures into spanish. *Arthritis and Rheumatism*, 38(10), 1429-1446.
- Goodacre, L., Smith, J., Meddis, D., & Goodacre, J. (2007). Development and validation of a patient-centred measure of activity limitation (MAL) in rheumatoid arthritis. *Rheumatology (Oxford, England)*, 46(4), 703-708.
- Green, C. R., & Hart-Johnson, T. (2010). The impact of chronic pain on the health of black and white men. *Journal of the National Medical Association*, 102(4), 321-331.
- Gregorich, S. E. (2006). Do self-report instruments allow meaningful comparisons across diverse population groups?: Testing measurement invariance using the confirmatory factor analysis framework. *Medical Care. Measurement in a Multi-Ethnic Society*, 44(11) (Suppl 3), S78-S94.
- Guillemin, F., Bombardier, C., & Beaton, D. (1993). Cross-cultural adaptation of health-related quality of life measures: Literature review and proposed guidelines. *Journal of Clinical Epidemiology*, 46(12), 1417-1432.
- Hakala, M., Nieminen, P., & Manelius, J. (1994). Joint impairment is strongly correlated with disability measured by self-report questionnaires. functional status assessment of individuals with rheumatoid arthritis in a population based series. *The Journal of Rheumatology*, 21(1), 64-69.

- Hallett, B. (2006). *Aboriginal People in Manitoba*. (No. SG5-2/2006E). Ottawa, Canada: Service Canada.
- Harkness, J., Pennell, B. E., & Schoua-Glusberg, A. (2004). Survey questionnaire translation and assessment. In S. Presser, J. M. Rothgeb, M. P. Couper, J. T. Lessler, E. Martin, J. Martin & E. Singer (Eds.), *Methods for testing and evaluating survey questionnaires* (pp. 453-473). Hoboken, New Jersey, USA: John Wiley & Sons, Inc.
- Hawker, G. A., Mian, S., Kendzerska, T., & French, M. (2011). Measures of adult pain: Visual analog scale for pain (VAS pain), numeric rating scale for pain (NRS pain), McGill pain questionnaire (MPQ), short-form McGill pain questionnaire (SF-MPQ), chronic pain grade scale (CPGS), short form-36 bodily pain scale (SF-36 BPS), and measure of intermittent and constant osteoarthritis pain (ICOAP). *Arthritis Care & Research*, 63(S11), S240-S252.
- Health Canada. (2008). First Nations, Inuit and Aboriginal health: Funded health programs and services. Retrieved from <http://www.hc-sc.gc.ca/fniah-spnia/finance/agree-accord/prog/index-eng.php#prim>
- Health Canada. (2011). Non-insured health benefits for First Nations and Inuit. Retrieved from <http://www.hc-sc.gc.ca/fniah-spnia/nihb-ssna/index-eng.php>
- Helewa, A., Goldsmith, C. H., & Smythe, H. A. (1982). Independent measurement of functional capacity in rheumatoid arthritis. *The Journal of Rheumatology*, 9(5), 794-797.
- Hernandez-Cruz, B., & Cardiel, M. H. (1998). Intra-observer reliability of commonly used outcome measures in rheumatoid arthritis. *Clinical and Experimental Rheumatology*, 16(4), 459-462.
- Hewlett, S. A. (2003). Patients and clinicians have different perspectives on outcomes in arthritis. *The Journal of Rheumatology*, 30(4), 877-879.
- Hidding, A., van Santen, M., De Klerk, E., Gielen, X., Boers, M., Geenen, R., van der Linden, S. (1994). Comparison between self-report measures and clinical observations of functional disability in ankylosing spondylitis, rheumatoid arthritis and fibromyalgia. *The Journal of Rheumatology*, 21(5), 818-823.
- Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277-1288.
- Hughes, J. G. (2009). "When I first started going I was going in on my knees, but I came out and I was skipping": Exploring rheumatoid arthritis patients' perceptions of receiving treatment with acupuncture. *Complementary Therapies in Medicine*, 17(5-6), 269-273.
- Hunt, S. M., Alonso, J., Bucquet, D., Niero, M., Wiklund, I., & McKenna, S. (1991). Cross-cultural adaptation of health measures. European group for health management and quality of life assessment. *Health Policy (Amsterdam, Netherlands)*, 19(1), 33-44.

- Hunt, S. M., & Bhopal, R. (2004). Self report in clinical and epidemiological studies with non-English speakers: The challenge of language and culture. *Journal of Epidemiology and Community Health, 58*(7), 618-622.
- Hunt, S. M., McKenna, S. P., McEwen, J., Backett, E. M., Williams, J., & Papp, E. (1980). A quantitative approach to perceived health status: A validation study. *Journal of Epidemiology and Community Health, 34*(4), pp. 281-286.
- Huskisson, E. C. (1974). Measurement of pain. *The Lancet, 2*, 1127-1131.
- Hwang, E. J., Kim, Y. H., & Jun, S. S. (2004). Lived experience of Korean women suffering from rheumatoid arthritis: A phenomenological approach. *International Journal of Nursing Studies, 41*(3), 239-246.
- Iwama, M. K., Thomson, N. A., & Macdonald, R. M. (2009). The Kawa model: The power of culturally responsive occupational therapy. *Disability & Rehabilitation, 31*(14), 1125-1135.
- Jamieson, L. M., Parker, E. J., & Richards, L. (2008). Using qualitative methodology to inform an Indigenous-owned oral health promotion initiative in Australia. *Health Promotion International, 23*(1), 52-59.
- Jette, A. M. (1980). Functional status index: Reliability of a chronic disease evaluation instrument. *Archives of Physical Medicine and Rehabilitation, 61*(9), 395-401.
- Jette, A. M. (1987). The functional status index: Reliability and validity of a self-report functional disability measure. *The Journal of Rheumatology. Supplement, 14 Suppl 15*, 15-21.
- Jette, A. M. (2006). Toward a common language for function, disability, and health. *Physical Therapy, 86*(5), 726-734.
- Jette, A. M., & Keysor, J. J. (2003). Disability models: Implications for arthritis exercise and physical activity interventions. *Arthritis and Rheumatism, 49*(1), 114-120.
- Jick, T. D. (1979). Mixing qualitative and quantitative methods: Triangulation in action. *Administrative Science Quarterly, 24*(4, Qualitative Methodology), 602-611.
- Jimenez, N., Garrouette, E., Kundu, A., Morales, L., & Buchwald, D. (2011). A review of the experience, epidemiology, and management of pain among American Indian, Alaska Native, and Aboriginal Canadian peoples. *The Journal of Pain : Official Journal of the American Pain Society, 12*(5), 511-522.
- Johnson, T. P. (2006). Methods and frameworks for crosscultural measurement. *Medical Care. Measurement in a Multi-Ethnic Society, 44*(11) (Suppl 3), S17-S20.
- Kane, R. L. (2000). Choosing and using an assessment tool. In R. L. Kane, & R. A. Kane (Eds.), *Assessing older persons: Measures, meaning, and practical applications* (pp. 1-13). New York, USA: Oxford University Press.

- Kapetanovic, M. C., Lindqvist, E., Nilsson, J., Geborek, P., Saxne, T., & Eberhardt, K. (2015). Development of functional impairment and disability in rheumatoid arthritis patients followed for 20 years: Relation to disease activity, joint damage, and comorbidity. *Arthritis Care & Research*, *67*(3), 340-348.
- Katz, P. P. (2005). Use of self-management behaviors to cope with rheumatoid arthritis stressors. *Arthritis and Rheumatism*, *53*(6), 939-949.
- Katz, P. P., Morris, A., & Yelin, E.H. (2006). Prevalence and predictors of disability in valued life activities among individuals with rheumatoid arthritis. *Annals of the Rheumatic Diseases* *65*, 763-769.
- Katz, P. P., & Morris, A. M. (2007). Use of accommodations for valued life activities: Prevalence and effects on disability scores. *Arthritis & Rheumatism* *57*(5), 730-737.
- Katz, S., Ford, A. B., Moskowitz, R. W., Jackson, B. A., & Jaffe, M. W. (1963). Studies of illness in the aged. the index of adl: A standardized measure of biological and psychosocial function. *JAMA : The Journal of the American Medical Association*, *185*, 914-919.
- Katz, P. P. (2011). Introduction to special issue: Patient outcomes in rheumatology, 2011. *Arthritis Care & Research*, *63 Suppl 11*, S1-3.
- Katz, S., Downs, T. D., Cash, H. R., & Grotz, R. C. (1970). Progress in development of the index of ADL. *The Gerontologist*, *10*(1), 20-30.
- Kaufert, J. M. (1983). Functional ability indices: Measurement problems in assessing their validity. *Archives of Physical Medicine and Rehabilitation*, *64*(6), 260-267.
- Kidd, T., & Yoshida, K. (1995). Critical review of disability measures: Conceptual developments. *Physiotherapy Canada. Physiotherapie Canada*, *47*(2), 108-119.
- Kiresuk, T. J., & Sherman, R. E. (1968). Goal attainment scaling: A general method for evaluating comprehensive community mental health programs. *Community Mental Health Journal*, *4*(6), 443-453.
- Kirkham, S. R., & Anderson, J. M. (2002). Postcolonial nursing scholarship: From epistemology to method. *ANS. Advances in Nursing Science*, *25*(1), 1-17.
- Kivela, S. L. (1984). Measuring disability--do self-ratings and service provider ratings compare? *Journal of Chronic Diseases*, *37*(2), 115-123.
- Kleinman, A. (1980). *Patients and healers in the context of culture*. Los Angeles, CA: University of California Press.
- Kleinman, A. (1988). *The illness narratives: Suffering, healing and the human condition*. New York, NY: Basic Books, Inc.

- Kleinman, A., Wang, W., Li, S., Cheng, X., Dai, X., Li, K., & Kleinman, J. (1995). The social course of epilepsy: Chronic illness as social experience in interior china. *Social Science & Medicine*, 40(10), 1319-1330.
- Kramer, B. J., Harker, J. O., & Wong, A. L. (2002). Descriptions of joint pain by American Indians: Comparison of inflammatory and noninflammatory arthritis. *Arthritis and Rheumatism*, 47(2), 149-154.
- Krause, N. (2006). The use of qualitative methods to improve quantitative measures of health-related constructs. *Medical Care. Measurement in a Multi-Ethnic Society*, 44(11) (Suppl 3), S34-S38.
- Kroll, T., Barbour, R., & Harris, J. (2007). Using focus groups in disability research. *Qualitative Health Research*, 17(5), 690-698.
- Kroll, T., Neri, M. T., & Miller, K. (2005). Using mixed methods in disability and rehabilitation research [corrected] [published erratum appears in REHABIL NURS 2005 jul-aug;30(4):146]. including commentary by Seacrest J. *Rehabilitation Nursing*, 30(3), 106-113.
- Kucukdeveci, A. A., Sahin, H., Ataman, S., Griffiths, B., & Tennant, A. (2004). Issues in cross-cultural validity: Example from the adaptation, reliability, and validity testing of a Turkish version of the Stanford health assessment questionnaire. *Arthritis and Rheumatism*, 51(1), 14-19.
- Kvien, T. K. (2004). Epidemiology and burden of illness of rheumatoid arthritis. *Pharmacoeconomics*, 22(2 Suppl 1), 1-12.
- Kwoh, C. K., O'Connor, G. T., Regan-Smith, M. G., Olmstead, E. M., Brown, L. A., Burnett, J. B., Morgan, G. J. (1992). Concordance between clinician and patient assessment of physical and mental health status. *The Journal of Rheumatology*, 19(7), 1031-1037.
- Lacaille, D., White, M. A., Backman, C. L., & Gignac, M. A. (2007). Problems faced at work due to inflammatory arthritis: New insights gained from understanding patients' perspective. *Arthritis and Rheumatism*, 57(7), 1269-1279.
- Lansbury, J. (1958). Numerical method of evaluating the status of rheumatoid arthritis. *Annals of the Rheumatic Diseases*, 17(1), 101-107.
- Lawton, M. P., & Brody, E. M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. *The Gerontologist*, 9(3), 179-186.
- Lempp, H., Scott, D., & Kingsley, G. (2006). The personal impact of rheumatoid arthritis on patients' identity: A qualitative study. *Chronic Illness*, 2(2), 109-120.
- Liang, M. H. (1987). The historical and conceptual framework for functional assessment in rheumatic disease. *The Journal of Rheumatology. Supplement*, 14 Suppl 15, 2-5.

- Lichtenstein, M. J., Dhanda, R., Cornell, J. E., Escalante, A., & Hazuda, H. P. (1998). Disaggregating pain and its effect on physical functional limitations. *The Journals of Gerontology. Series A, Biological Sciences and Medical Sciences*, 53(5), M361-71.
- Lillegraven, S., & Kvien, T. K. (2007). Measuring disability and quality of life in established rheumatoid arthritis. *Best Practice & Research. Clinical Rheumatology*, 21(5), 827-840.
- Linde, L., Sorensen, J., Ostergaard, M., Horslev-Petersen, K., Rasmussen, C., Jensen, D. V., & Hetland, M. L. (2009). What factors influence the health status of patients with rheumatoid arthritis measured by the SF-12v2 health survey and the health assessment questionnaire? *The Journal of Rheumatology*, 36(10), 2183-2189.
- Lopez, G. I., Figueroa, M., Connor, S. E., & Maliski, S. L. (2008). Translation barriers in conducting qualitative research with Spanish speakers. *Qualitative Health Research*, 18(12), 1729-1737.
- Lubeck, D. P. (2002). Health-related quality of life measurements and studies in rheumatoid arthritis. *American Journal of Managed Care*, 8(9), 811-820.
- Maar, M. A., Lightfoot, N. E., Sutherland, M. E., Strasser, R. P., Wilson, K. J., Lidstone-Jones, C. M., Williamson, P. (2011). Thinking outside the box: Aboriginal people's suggestions for conducting health studies with Aboriginal communities. *Public Health*, 125(11), 747-753.
- MacKay, C., Sale, J., Badley, E., M., Jaglal, S., B., & Davis, A., M. (2015). A qualitative study exploring the meaning of knee symptoms to adults aged 35-65 years. *Arthritis Care & Research*. doi: 10.1002/acr.22664.
- Maetzel, A., Li, L. C., Pencharz, J., Tomlinson, G., Bombardier, C., & Community Hypertension and Arthritis Project Study Team. (2004). The economic burden associated with osteoarthritis, rheumatoid arthritis, and hypertension: A comparative study. *Annals of the Rheumatic Diseases*, 63(4), 395-401.
- Mahoney, F. I., & Barthel, D. W. (1965). Functional evaluation: The Barthel index. *Maryland State Medical Journal*, 14, 61-65.
- Manly, J. J. (2006). Deconstructing race and ethnicity: Implications for measurement of health outcomes. *Medical Care. Measurement in a Multi-Ethnic Society*, 44(11) (Suppl 3), S10-S16.
- Maradit-Kremers, H., Nicola, P. J., Crowson, C. S., Ballman, K. V., & Gabriel, S. E. (2005). Cardiovascular death in rheumatoid arthritis: A population-based study. *Arthritis and Rheumatism*, 52(3), 722-732.
- March, L., Smith, E. U. R., Hoy, D. G., Cross, M. J., Sanchez-Riera, L., Blyth, F., Woolf, A. D. (2014). Burden of disability due to musculoskeletal (MSK) disorders. *Best Practice & Research Clinical Rheumatology*, 28(3), 353-366.

- Marshall, P., & Murphy, B. (2008). Self-report measures best explain changes in disability compared with physical measures after exercise rehabilitation for chronic low back pain. *Spine*, 33(3), 326-338.
- Maska, L., Anderson, J., & Michaud, K. (2011). Measures of functional status and quality of life in rheumatoid arthritis: Health assessment questionnaire disability index (HAQ), modified health assessment questionnaire (MHAQ), multidimensional health assessment questionnaire (MDHAQ), health assessment questionnaire II (HAQ-II), improved health assessment questionnaire (improved HAQ), and rheumatoid arthritis quality of life (RAQoL). *Arthritis Care & Research*, 63(S11), S4-S13.
- Mason, J. H., Anderson, J. J., Meenan, R. F., Haralson, K. M., Lewis-Stevens, D., & Kaine, J. L. (1992). The rapid assessment of disease activity in rheumatology (radar) questionnaire. validity and sensitivity to change of a patient self-report measure of joint count and clinical status. *Arthritis and Rheumatism*, 35(2), 156-162.
- Mastos, M., Miller, K., Eliasson, A., & Imms, C. (2007). Goal-directed training: Linking theories of treatment to clinical practice for improved functional activities in daily life. *Clinical Rehabilitation*, 21(1), 47-55.
- Matheson, L., Harcourt, D., & Hewlett, S. (2010). 'Your whole life, your whole world, it changes': Partners' experiences of living with rheumatoid arthritis. *Musculoskeletal Care*, 8(1), 46-54.
- McDowell, I. (2006). *Measuring health: A guide to rating scales and questionnaires* (3rd ed.). Toronto, Canada: Oxford University Press Inc.
- McHorney, C. A., Ware, J. E., Jr, Lu, J. F., & Sherbourne, C. D. (1994). The MOS 36-item short-form health survey (SF-36): III. tests of data quality, scaling assumptions, and reliability across diverse patient groups. *Medical Care*, 32(1), 40-66.
- McInnes, I. B., & Schett, G. (2011). The pathogenesis of rheumatoid arthritis. *The New England Journal of Medicine*, 365(23), 2205-2219.
- McSweeney, J. C., Allan, J. D., & Mayo, K. (1997). Exploring the use of explanatory models in nursing research and practice. *Image: The Journal of Nursing Scholarship*, 29(3), 243-248.
- Meana, M., Cho, R., & DesMeules, M. (2004). Chronic pain: The extra burden on Canadian women. *BMC Women's Health*, 4 Suppl 1, S17.
- Meenan, R. F., Gertman, P. M., & Mason, J. H. (1980). Measuring health status in arthritis. the arthritis impact measurement scales. *Arthritis and Rheumatism*, 23(2), 146-152.
- Meenan, R. F., Mason, J. H., Anderson, J. J., Guccione, A. A., & Kazis, L. E. (1992). AIMS2. the content and properties of a revised and expanded arthritis impact measurement scales health status questionnaire. *Arthritis and Rheumatism*, 35(1), 1-10.

- Melzack, R. (1975). The McGill pain questionnaire: Major properties and scoring methods. *Pain*, 1(3), 277-299.
- Meredith, W., & Teresi, J. A. (2006). An essay on measurement and factorial invariance. *Medical Care*, 44(11 (S3)), S69-S77.
- Michel, B. A., Bloch, D. A., & Fries, J. F. (1991). Predictors of fractures in early rheumatoid arthritis. *The Journal of Rheumatology*, 18(6), 804-808.
- Mignone, J., & O'Neil, J. (2005). Social capital and youth suicide risk factors in first nations communities. *Canadian Journal of Public Health*, 96, S51.
- Mikuls, T. R. (2003). Co-morbidity in rheumatoid arthritis. *Best Practice & Research. Clinical Rheumatology*, 17(5), 729-752.
- Mills, J., Bonner, A., & Francis, K. (2006). The development of constructivist grounded theory. *International Journal of Qualitative Methods*, 5(1)
- Mirmirani, P. (2013). Managing hair loss in midlife women. *Maturitas*, 74(2), 119-122.
- Moghaddam, F. M., Walker, B. R., & Harré, R. (2003). Cultural distance, levels of abstraction, and the advantages of mixed methods. *Handbook of mixed methods in social and behavioral research* (pp. 111-134). Thousand Oaks, CA, USA: Sage.
- Morse, J. M., Young, D. E., & Swartz, L. (1991). Cree Indian healing practices and western health care: A comparative analysis. *Social Science & Medicine* (1982), 32(12), 1361-1366.
- Neogi, T., Aletaha, D., Silman, A. J., Naden, R. L., Felson, D. T., Aggarwal, R., European League Against Rheumatism. (2010). The 2010 American college of rheumatology/European league against rheumatism classification criteria for rheumatoid arthritis: Phase 2 methodological report. *Arthritis and Rheumatism*, 62(9), 2582-2591.
- Neville, C., Whalley, D., McKenna, S., Le Comte, M., & Fortin, P. R. (2001). Adaptation and validation of the rheumatoid arthritis quality of life scale for use in Canada. *The Journal of Rheumatology*, 28(7), 1505-1510.
- O'Cathain, A., Murphy, E., & Nicholl, J. (2010). Three techniques for integrating data in mixed methods studies. *BMJ (Clinical Research Ed.)*, 341, c4587.
- O'Dell, J. R. (2002). Treating rheumatoid arthritis early: A window of opportunity? *Arthritis and Rheumatism*, 46(2), 283-285.
- Oliver, M. (1998). Theories in health care and research: Theories of disability in health practice and research. *BMJ (Clinical Research Ed.)*, 317(7170), 1446-1449.
- Oliver, S. (2003). Multidisciplinary disease management in rheumatology. *Professional Nurse (London, England)*, 19(3), 137-141.

- Osiri, M., Wongchinsri, J., Ukritchon, S., Hanvivadhanakul, P., Kasitanon, N., & Siripaitoon, B. (2009). Comprehensibility, reliability, validity, and responsiveness of the Thai version of the health assessment questionnaire in Thai patients with rheumatoid arthritis. *Arthritis Research & Therapy*, *11*(4), R129.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.
- Paulus, H. E., & Bulpitt, K. J. (1995). Rheumatoid arthritis. outcome measures. *Rheumatic Diseases Clinics of North America*, *21*(3), 605-618.
- Paulus, H. E., Egger, M. J., Ward, J. R., & Williams, H. J. (1990). Analysis of improvement in individual rheumatoid arthritis patients treated with disease-modifying antirheumatic drugs, based on the findings in patients treated with placebo. the cooperative systematic studies of rheumatic diseases group. *Arthritis and Rheumatism*, *33*(4), 477-484.
- Pearson, V. I. (2000). Assessment of function in older adults. In R. L. Kane, & R. A. Kane (Eds.), *Assessing older persons: Measures, meaning and practical applications* (pp. 17-48). New York, USA: Oxford University Press.
- Peschken, C. (2013). The value of studying clinical and serologic phenotypes in north American Native populations with autoimmune disease. *The Journal of Rheumatology*, *40*(7), 1031-1033.
- Peschken, C. A., & Esdaile, J. M. (1999). Rheumatic diseases in North America's Indigenous peoples. *Seminars in Arthritis and Rheumatism*, *28*(6), 368-391.
- Peschken, C. A., Hitchon, C. A., Robinson, D. B., Smolik, I., Barnabe, C. R., Prematilake, S., & El-Gabalawy, H. S. (2010). Rheumatoid arthritis in a North American Native population: Longitudinal followup and comparison with a white population. *The Journal of Rheumatology*, *37*(8), 1589-1595.
- Peschken, C. A., Robinson, D. B., Hitchon, C. A., Smolik, I., Hart, D., Bernstein, C. N., & El-Gabalawy, H. S. (2012). Pregnancy and the risk of rheumatoid arthritis in a highly predisposed north American Native population. *The Journal of Rheumatology*, *39*(12), 2253-2260.
- Phinney, J. S. (1996). Understanding ethnic diversity: The role of ethnic identity. *American Behavioral Scientist*, *40*, 143-152.
- Pincus, T. (2005). The American college of rheumatology (ACR) core data set and derivative "patient only" indices to assess rheumatoid arthritis. *Clinical and Experimental Rheumatology*, *23*(5 Suppl 39), S109-13.
- Pincus, T., Bergman, M., Sokka, T., Roth, J., Swearingen, C., & Yazici, Y. (2008). Visual analog scales in formats other than a 10 centimeter horizontal line to assess pain and other clinical data. *The Journal of Rheumatology*, *35*(8), 1550-1558.

- Pincus, T., & Sokka, T. (2003). Quantitative measures for assessing rheumatoid arthritis in clinical trials and clinical care. *Best Practice & Research. Clinical Rheumatology*, 17(5), 753-781.
- Pincus, T., Summey, J. A., Soraci, S. A., Jr, Wallston, K. A., & Hummon, N. P. (1983). Assessment of patient satisfaction in activities of daily living using a modified Stanford health assessment questionnaire. *Arthritis and Rheumatism*, 26(11), 1346-1353.
- Pincus, T., Swearingen, C., & Wolfe, F. (1999). Toward a multidimensional health assessment questionnaire (MDHAQ): Assessment of advanced activities of daily living and psychological status in the patient-friendly health assessment questionnaire format. *Arthritis and Rheumatism*, 42(10), 2220-2230.
- Pincus, T., Yazici, Y., & Sokka, T. (2007). Quantitative measures of rheumatic diseases for clinical research versus standard clinical care: Differences, advantages and limitations. *Best Practice & Research Clinical Rheumatology*, 21(4), 601-628.
- Pinheiro, F. A., Souza, D. C., & Sato, E. I. (2015). A study of multiple causes of death in rheumatoid arthritis. *The Journal of Rheumatology*, 42(12), 2221-2228.
- Polaschek, N. R. (1998). Cultural safety: A new concept in nursing people of different ethnicities. *Journal of Advanced Nursing*, 27(3), 452-457.
- Prevo, M. L., van 't Hof, M. A., Kuper, H. H., van Leeuwen, M. A., van de Putte, L. B., & van Riel, P. L. (1995). Modified disease activity scores that include twenty-eight-joint counts. development and validation in a prospective longitudinal study of patients with rheumatoid arthritis. *Arthritis and Rheumatism*, 38(1), 44-48.
- Public Health Agency of Canada. (2010). *Life with arthritis in Canada: A personal and public health challenge*. Ottawa: PHAC.
- Quinlan, I., Hirsh, J. M., Bright, C., & Caplan, L. (2015). Cross-sectional correlation of single-item health literacy screening questions with established measures of health literacy in patients with rheumatoid arthritis. *Rheumatology International*, doi:10.1007/s00296-015-3238-9 [doi]
- Ramsden, I. (1990). Cultural safety. *The New Zealand Nursing Journal. Kai Tiaki*, 83(11), 18-19.
- Ramsden, I. (2000). Cultural safety/kawa whakaruruhau ten years on: A personal overview. *Nursing Praxis in New Zealand Inc*, 15(1), 4-12.
- Ren, X. S., & Amick, C. (1998). Cross-cultural use of measurements. In S. Loue (Ed.), *Handbook of immigrant health* (pp. 81-99). New York, USA: Plenum Press.
- Richmond, C. A., & Ross, N. A. (2008). Social support, material circumstance and health behaviour: Influences on health in First Nation and Inuit communities of Canada. *Social Science & Medicine* (1982), 67(9), 1423-1433.

- Ripat, J., Etcheverry, E., Cooper, J., & Tate, R. B. (2001). A comparison of the Canadian occupational performance measure and the health assessment questionnaire. *Canadian Journal of Occupational Therapy. Revue Canadienne D'Ergotherapie*, 68(4), 247-253.
- Ripat, J., & Woodgate, R. (2011). The intersection of culture, disability and assistive technology. *Disability and Rehabilitation Assistive Technology*, 6(2), 87-96.
- Ritchie, D. M., Boyle, J. A., McInnes, J. M., Jasani, M. K., Dalakos, T. G., Grieveson, P., & Buchanan, W. W. (1968). Clinical studies with an articular index for the assessment of joint tenderness in patients with rheumatoid arthritis. *The Quarterly Journal of Medicine*, 37(147), 393-406.
- Rohekar, G., & Pope, J. (2009). Test-retest reliability of patient global assessment and physician global assessment in rheumatoid arthritis. *The Journal of Rheumatology*, 36(10), 2178-2182.
- Rothman, J. C. (2010). The challenge of disability and access: Reconceptualizing the role of the medical model. *Journal of Social Work in Disability & Rehabilitation*, 9(2-3), 194-222.
- Rothschild, B. M., & Woods, R. J. (1990). Symmetrical erosive disease in archaic Indians: The origin of rheumatoid arthritis in the new world? *Seminars in Arthritis and Rheumatism*, 19(5), 278-284.
- Rouquette, A., Badley, E. M., Falissard, B., Dub, T., Leplege, A., & Coste, J. (2015). Moderators, mediators, and bidirectional relationships in the international classification of functioning, disability and health (ICF) framework: An empirical investigation using a longitudinal design and structural equation modeling (SEM). *Social Science & Medicine (1982)*, 135, 133-142.
- Royal Commission on Aboriginal Peoples. (1996). *Report of the royal commission on Aboriginal peoples: Volume 5. renewal: A twenty-year commitment.* (). Ottawa, Canada: Minister of Supply and Services Canada.
- Russak, S. M., Croft, J. D., Jr, Furst, D. E., Hohlbauch, A., Liang, M. H., Moreland, L. Evidence-Based Medicine Working Groups in Rheumatology. (2003). The use of rheumatoid arthritis health-related quality of life patient questionnaires in clinical practice: Lessons learned. *Arthritis and Rheumatism*, 49(4), 574-584.
- Salaffi, F., Bazzichi, L., Stancati, A., Neri, R., Cazzato, M., Consensi, A. Bombardieri, S. (2005). Development of a functional disability measurement tool to assess early arthritis: The recent-onset arthritis disability (ROAD) questionnaire. *Clinical and Experimental Rheumatology*, 23(5), 628-636.
- Salazar, L. F., Crosby, R. A., & DiClemente, R. J. (2006). Choosing a research design. In R. A. Crosby, R. J. DiClemente & L. F. Salazar (Eds.), *Research methods in health promotion* (pp. 75-105). New York, USA: Jossey-Bass.

- Sandelowski, M. (2000). Combining qualitative and quantitative sampling, data collection, and analysis techniques in mixed-method studies. *Research in Nursing & Health, 23*(3), 246-255.
- Schneider, M., Manabile, E., & Tikly, M. (2008). Social aspects of living with rheumatoid arthritis: A qualitative descriptive study in Soweto, South Africa - a low resource context. *Health and Quality of Life Outcomes, 6*, 54.
- Scott, D. L. (2002). The diagnosis and prognosis of early arthritis: Rationale for new prognostic criteria. *Arthritis and Rheumatism, 46*(2), 286-290.
- Shakespeare, T. (2005a). Disability, genetics and global justice. *Social Policy & Society, 4*(1), 87-95.
- Shakespeare, T. (2005b). Review article: Disability studies today and tomorrow. *Sociology of Health & Illness, 27*(1), 138-148.
- Shakespeare, T., Iezzoni, L. I., & Groce, N. E. (2009). Disability and the training of health professionals. *The Lancet, 374*(9704), 1815-1816.
- Schau, T., Gottwald, M., Arbach, O., Seifert, M., Schopp, M., Neuss, M., . . . Zanker, M. (2015). Increased prevalence of diastolic heart failure in patients with rheumatoid arthritis correlates with active disease, but not with treatment type. *The Journal of Rheumatology, 42*(11), 2029-2037.
- Schneider, M., Manabile, E., & Tikly, M. (2008). Social aspects of living with rheumatoid arthritis: A qualitative descriptive study in Soweto, South Africa - a low resource context. *Health and Quality of Life Outcomes, 6*, 54.
- Silman, A. J., & Pearson, J. E. (2002). Epidemiology and genetics of rheumatoid arthritis. *Arthritis Research, 4 Suppl 3*, S265-72.
- Slevin, M. L., Plant, H., Lynch, D., Drinkwater, J., & Gregory, W. M. (1988). Who should measure quality of life, the doctor or the patient? *British Journal of Cancer, 57*(1), 109-112.
- Smolen, J. S., Breedveld, F. C., Schiff, M. H., Kalden, J. R., Emery, P., Eberl, G. Tugwell, P. (2003). A simplified disease activity index for rheumatoid arthritis for use in clinical practice. *Rheumatology (Oxford, England), 42*(2), 244-257.
- Smolik, I., Robinson, D. B., Bernstein, C. N., & El-Gabalawy, H. S. (2013). First-degree relatives of patients with rheumatoid arthritis exhibit high prevalence of joint symptoms. *The Journal of Rheumatology, 40*(6), 818-824.
- Sokka, T. (2003). Assessment of pain in patients with rheumatic diseases. *Best Practice & Research. Clinical Rheumatology, 17*(3), 427-449.

- Spencer, S. M., Albert, S. M., Bear-Lehman, J., & Burkhardt, A. (2008). Relevance of race and ethnicity for self-reported functional limitation. *Journal of the American Geriatrics Society*, 56(3), 553-557.
- Squires, A. (2009). Methodological challenges in cross-language qualitative research: A research review. *International Journal of Nursing Studies*, 46(2), 277-287.
- Statistics Canada. (2013). *Aboriginal Peoples in Canada: First Nations People, Métis and Inuit; National Household Survey 2011*. (No. Catalogue no. 99-011-X2011001). Ottawa, Canada: Minister of Industry.
- Steinbrocker, O., & Blazer, A. (1946). A therapeutic score card for rheumatoid arthritis; a standardized method of appraising results of treatment. *The New England Journal of Medicine*, 235, 501-506.
- Stewart, A. L., Hays, R. D., & Ware, J. E., Jr. (1988). The MOS short-form general health survey. reliability and validity in a patient population. *Medical Care*, 26(7), 724-735.
- Stratford, P., Gill, C., Westaway, M., & Binkley, J. (1995). Assessing disability and change on individual patients: A report of a patient specific measure. *Physiotherapy Canada*, 47(4), 258-263.
- Strickland, C. J. (1999a). Conducting focus groups cross-culturally: Experiences with Pacific Northwest Indian People. *Public Health Nursing*, 16(3), 190-197.
- Strickland, C. J. (1999b). The importance of qualitative research in addressing cultural relevance: Experiences from research with Pacific Northwest Indian women. *Health Care for Women International*, 20(5), 517-525.
- Strong, J., Nielsen, M., Williams, M., Huggins, J., & Sussex, R. (2015). Quiet about pain: Experiences of Aboriginal people in two rural communities. *The Australian Journal of Rural Health*, 23(3), 181-184.
- Stucki, G., & Cieza, A. (2004). The international classification of functioning, disability and health (ICF) core sets for rheumatoid arthritis: A way to specify functioning. *Annals of the Rheumatic Diseases*, 63 Suppl 2, ii40-ii45.
- Stucki, G., Cieza, A., Geyh, S., Battistella, L., Lloyd, J., Symmons, D.Schouten, J. (2004). ICF core sets for rheumatoid arthritis. *Journal of Rehabilitation Medicine Supplement*, 36(44), 87-93.
- Stucki, G., Liang, M. H., Stucki, S., Bruhlmann, P., & Michel, B. A. (1995). A self-administered rheumatoid arthritis disease activity index (RADAI) for epidemiologic research. psychometric properties and correlation with parameters of disease activity. *Arthritis and Rheumatism*, 38(6), 795-798.

- Stucki, G., Stucki, S., Bruhlmann, P., Maus, S., & Michel, B. A. (1995). Comparison of the validity and reliability of self-reported articular indices. *British Journal of Rheumatology*, 34(8), 760-766.
- Stucki, G., Stucki, S., Bruhlmann, P., & Michel, B. A. (1995). Ceiling effects of the health assessment questionnaire and its modified version in some ambulatory rheumatoid arthritis patients. *Annals of the Rheumatic Diseases*, 54(6), 461-465.
- Suter, L. G., Fraenkel, L., & Holmboe, E. S. (2006). What factors account for referral delays for patients with suspected rheumatoid arthritis? *Arthritis and Rheumatism*, 55(2), 300-305.
- Symmons, D. P. (2005). Looking back: Rheumatoid arthritis - aetiology, occurrence and mortality. *Rheumatology (Oxford)*, 44(Suppl. 4), iv14-iv17.
- Tammaru, M., Strompl, J., Maimets, K., & Hanson, E. (2004). The value of the qualitative method for adaptation of a disease-specific quality of life assessment instrument: The case of the rheumatoid arthritis quality of life scale (RAQoL) in Estonia. *Health and Quality of Life Outcomes*, 2, 69.
- Tavares, R., Wells, G. A., Bykerk, V. P., Guillemin, F., Tugwell, P., & Bell, M. J. (2013). Validation of a self-administered inflammatory arthritis detection tool for rheumatology triage. *The Journal of Rheumatology*, 40(4), 417-424.
- Templin, D. W., Boyer, G. S., Lanier, A. P., Nelson, J. L., Barrington, R. A., Hansen, J. A., Carlsen, R. (1994). Rheumatoid arthritis in Tlingit Indians: Clinical characterization and HLA associations. *The Journal of Rheumatology*, 21(7), 1238-1244.
- Thomas, C. (2004). How is disability understood? an examination of sociological approaches. *Disability & Society*, 19(6), 569-583.
- Thompson, P. W. (1988). Functional outcome in rheumatoid arthritis. *British Journal of Rheumatology*, 27 Suppl 1, 37-43.
- Thorne, S. (2008). *Interpretive description*. Walnut Creek California: Left Coast Press Inc.
- Thorne, S., Reimer Kirkham, S., & MacDonald-Emes, J. (1997). Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing and Health*, 20(2), 169-177.
- Thorne, S., Reimer Kirkham, S., & O'Flynn-Magee, K. (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods*, 3(1) Retrieved from http://www.ualberta.ca/~iiqm/backissues/3_1/pdf/thorneetal.pdf
- Thorne, S. (2011). Toward methodological emancipation in applied health research. *Qualitative Health Research*, 21(4), 443-453.

- Thorne, S. E., Oliffe, J. L., Oglov, V., & Gelmon, K. (2013). Communication challenges for chronic metastatic cancer in an era of novel therapeutics. *Qualitative Health Research, 23*(7), 863-875.
- Tijhuis, G. J., de Jong, Z., Zwinderman, A. H., Zuijderduin, W. M., Jansen, L. M., Hazes, J. M., & Vliet Vlieland, T. P. (2001). The validity of the rheumatoid arthritis quality of life (RAQoL) questionnaire. *Rheumatology (Oxford, England), 40*(10), 1112-1119.
- Tugwell, P., Bombardier, C., Buchanan, W. W., Goldsmith, C. H., Grace, E., & Hanna, B. (1987). The MACTAR patient preference disability questionnaire--an individualized functional priority approach for assessing improvement in physical disability in clinical trials in rheumatoid arthritis. *The Journal of Rheumatology, 14*(3), 446-451.
- Uhlig, T., Kvien, T. K., & Pincus, T. (2009). Test-retest reliability of disease activity core set measures and indices in rheumatoid arthritis. *Annals of the Rheumatic Diseases, 68*(6), 972-975.
- Uhlig, T., Moe, R., Reinsberg, S., Kvien, T. K., Cieza, A., & Stucki, G. (2009). Responsiveness of the international classification of functioning, disability and health (ICF) core set for rheumatoid arthritis. *Annals of the Rheumatic Diseases, 68*(6), 879-884.
- United Nations. (2007). United Nations adopts Declaration on Rights of Indigenous Peoples. Retrieved from <http://www.un.org/apps/news/story.asp?NewsID=23794>
- Üstün, T. B., Chatterji, S., Bickenbach, J. E., Trotter II, R. T., & Saxena, S. (2001). Disability and cultural variation: The ICIDH-2 cross-cultural applicability research study. In T. B. Üstün, S. Chatterji, J. E. Bickenbach, R. T. Trotter II, R. Room, J. Rehm & S. Saxena (Eds.), *Disability and culture: Universalism and diversity* (pp. 3-19). Toronto, ON: Hogrefe & Huber.
- Üstün, T. B., Kostanjsek, N., Chatterji, S., & Rehm, J. (Eds.) (2010). Measuring health and disability: Manual for WHO Disability Assessment Schedule. WHODAS 2.0. Retrieved from http://apps.who.int/iris/bitstream/10665/43974/1/9789241547598_eng.pdf.
- van Aken, J., van Bilsen, J. H., Allaart, C. F., Huizinga, T. W., & Breedveld, F. C. (2003). The Leiden early arthritis clinic. *Clinical and Experimental Rheumatology, 21*(5 Suppl 31), S100-5.
- van der Heijde, D. M., van 't Hof, M., van Riel, P. L., & van de Putte, L. B. (1993). Development of a disease activity score based on judgment in clinical practice by rheumatologists. *The Journal of Rheumatology, 20*(3), 579-581.
- van der Linden, M. P., le Cessie, S., Raza, K., van der Woude, D., Knevel, R., Huizinga, T. W., & van der Helm-van Mil, A. H. (2010). Long-term impact of delay in assessment of early arthritis patients. *Arthritis and Rheumatism, 62*(12), 3537-3546.
- Veehof, M. M., Taal, E., Willems, M. J., & van de Laar, M. A. (2008). Determinants of the use of wrist working splints in rheumatoid arthritis. *Arthritis and Rheumatism, 59*(4), 531-536.

- Verbrugge, L. M., & Jette, A. M. (1994). The disablement process. *Social Science & Medicine* (1982), 38(1), 1-14.
- Verhoeven, A. C., Boers, M., & van der Liden, S. (2000). Validity of the MACTAR questionnaire as a functional index in a rheumatoid arthritis clinical trial. the McMaster Toronto arthritis. *The Journal of Rheumatology*, 27(12), 2801-2809.
- Vliet Vlieland, T. P., Li, L. C., MacKay, C., Bombardier, C., & Badley, E. M. (2006). Current topics on models of care in the management of inflammatory arthritis. *The Journal of Rheumatology*, 33(9), 1900-1903.
- Wade, D. T., & de Jong, B. A. (2000). Recent advances in rehabilitation. *BMJ (Clinical Research Ed.)*, 320(7246), 1385-1388.
- Wakefield, R. J., Gibbon, W. W., Conaghan, P. G., O'Connor, P., McGonagle, D., Pease, C., Emery, P. (2000). The value of sonography in the detection of bone erosions in patients with rheumatoid arthritis: A comparison with conventional radiography. *Arthritis and Rheumatism*, 43(12), 2762-2770.
- Wallace, L. S., Rogers, E. S., Roskos, S. E., Holiday, D. B., & Weiss, B. D. (2006). Brief report: Screening items to identify patients with limited health literacy skills. *Journal of General Internal Medicine*, 21(8), 874-877.
- Ware, J. E., Jr, Keller, S. D., Gandek, B., Brazier, J. E., & Sullivan, M. (1995). Evaluating translations of health status questionnaires. Methods from the IQOLA project. International Quality of Life Assessment. *International Journal of Technology Assessment in Health Care*, 11(3), 525-551.
- Ware, J. E., Jr, & Sherbourne, C. D. (1992). The MOS 36-item short-form health survey (SF-36). I. conceptual framework and item selection. *Medical Care*, 30(6), 473-483.
- White, D. K., Wilson, J. C., & Keysor, J. J. (2011). Measures of adult general functional status. *Arthritis Care & Research*, 63(S11), S297-S307.
- Wiklund, I. (1990). The Nottingham health profile--a measure of health-related quality of life. *Scandinavian Journal of Primary Health Care. Supplement*, 1, 15-18.
- Williams, A. E., Nester, C. J., & Ravey, M. I. (2007). Rheumatoid arthritis patients' experiences of wearing therapeutic footwear - a qualitative investigation. *BMC Musculoskeletal Disorders*, 8, 104.
- Williams, G. H. (1987). Disablement and the social context of daily activity. *International Disability Studies*, 9(3), 97-102.
- Williams, G. H. (1986). Lay beliefs about the causes of rheumatoid arthritis: Their implications for rehabilitation. *International Rehabilitation Medicine*, 8(2), 65-68.

- Williams, G. H., & Wood, P. H. N. (1986). Common-sense beliefs about illness: A mediating role for the doctor. *The Lancet*, 328(8521–8522), 1435-1437.
- Williamson, G. R. (2005). Illustrating triangulation in mixed-methods nursing research. *Nurse Researcher*, 12(4), 7-18.
- Wolfe, F. (2000). A reappraisal of HAQ disability in rheumatoid arthritis. *Arthritis and Rheumatism*, 43(12), 2751-2761.
- Wolfe, F. (2001). Which HAQ is best? A comparison of the HAQ, MHAQ and RA-HAQ, a difficult 8 item HAQ (DHAQ), and a rescored 20 item HAQ (HAQ20): Analyses in 2,491 rheumatoid arthritis patients following leflunomide initiation. *The Journal of Rheumatology*, 28(5), 982-989.
- Wolfe, F., & Hawley, D. J. (1998). The long-term outcomes of rheumatoid arthritis: Work disability: A prospective 18 year study of 823 patients. *The Journal of Rheumatology*, 25(11), 2108-2117.
- World Health Organization. (2001). *International classification of functioning, disability and health (ICF)*. World Health Organization. Retrieved from <http://www.who.int/classifications/icf/en/>
- World Health Organization. (2003). *The burden of musculoskeletal conditions at the start of the new millennium*. (No. 919). Geneva: World Health Organization. Retrieved from http://www.who.int/trs/WHO_TRS_919.pdf
- World Health Organization. (2004). *A glossary of terms for community health care and services for older persons*. (No. WHO/WKC/Tech.Ser./04.2). Geneva: World Health Organization. Retrieved from http://www.who.int/wkc/2004/WHO_WKC_Tech.Ser._04.2.pdf
- Wright, J., Cross, J., & Lamb, S. (1998). Physiotherapy outcome measures for rehabilitation of elderly people: Responsiveness to change of the Rivermead mobility index and Barthel index. *Physiotherapy*, 84(5), 216-221.
- Young, A., Dixey, J., Cox, N., Davies, P., Devlin, J., Emery, P., Winfield, J. (2000). How does functional disability in early rheumatoid arthritis (RA) affect patients and their lives? Results of 5 years of follow-up in 732 patients from the early RA study (ERAS). *Rheumatology (Oxford, England)*, 39(6), 603-611.
- Ziebland, S., Fitzpatrick, R., Jenkinson, C., Mowat, A., & Mowat, A. (1992). Comparison of two approaches to measuring change in health status in rheumatoid arthritis: The health assessment questionnaire (HAQ) and modified HAQ. *Annals of the Rheumatic Diseases*, 51(11), 1202-1205.
- Zinke, J. L., Lam, C. S., Harden, R. N., & Fogg, L. (2010). Examining the cross-cultural validity of the English short-form McGill pain questionnaire using the matched moderated regression methodology. *The Clinical Journal of Pain*, 26(2), 153-162.

Glossary

Aboriginal Peoples refers to organic political and cultural entities that stem historically from the original peoples of North America, rather than collections of individuals united by so-called 'racial' characteristics. The term includes the First Nations (Indian), Inuit and Métis Peoples of Canada (Royal Commission on Aboriginal Peoples, 1996) .

Activity refers to the execution of a task or action by an individual (World Health Organization, 2001).

Activity limitations are difficulties an individual may have in executing activities (World Health Organization, 2001).

Capacity describes an individual's ability to execute a task or an action. Capacity reflects the environmentally-adjusted ability of the individual in a specified domain and assumes a person's capacity without personal assistance or the use of assistive devices. (World Health Organization, 2001).

Concurrent validity refers to the validity indicated by comparing scores on a measurement with those obtained by applying alternative, equivalent measurements at the same time (McDowell, 2006).

Convergent validity refers to the extent to which two or more instruments that purport to be measuring the same topic agree with each other (McDowell, 2006).

Construct validity refers to comparing the results of other contrasting tests of validity (including concurrent, convergent, and divergent validation studies) with predictions from a theoretical model. It is utilized when there is no other criterion against which to assess the validity of a measurement (McDowell, 2006).

Criterion validity refers to the extent that a measure correlates with the gold standard measure of the concept (Katz, 2011).

Disability is an umbrella term for impairments, activity limitations and participation restrictions (World Health Organization, 2001). Previously the term referred to any restriction or lack of ability to perform an activity in a manner or within the range considered normal for a human being (World Health Organization, 1980).

Disablement refers to impacts that chronic and acute conditions have on the functioning of specific body systems and on people's abilities to act in necessary, usual, expected and personally desired ways in their society (Verbrugge & Jette, 1994).

Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives (World Health Organization, 2001).

Function can be described as an umbrella term for body structures and functions, activities and participation (WHO, 2001).

Handicap was a term formerly used to refer to the disadvantage that limits or prevents the fulfillment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual (World Health Organization, 1980).

Impairments are problems in body functions or structures such as a significant deviation or loss (World Health Organization, 2001). The term formerly referred to any loss or abnormality of psychological, physiological or anatomical structure or function (World Health Organization, 1980).

Participation refers to a person's involvement in a life situation. It can be further qualified by "performance" (what an individual does in his/her current environment as influenced by the physical, social and attitudinal surroundings) or by "capacity" (what an individual can do in a standardized environmentally adjusted situation) (World Health Organization, 2001).

Participation restrictions are the problems an individual may experience in involvement in life situations. It represents the societal perspective of functioning (World Health Organization, 2001).

Performance describes what an individual does in his/her current environment. It can be interpreted as "involvement in a life situation" or the "lived experience" of people in their actual context (World Health Organization, 2001).

Postcolonialism refers to theoretical and empirical work that centralizes the issues stemming from colonial relationships and their aftermath (Kirkham & Anderson, 2002). The term postcolonialism does not refer to a period of time; the "post" refers to both working against and beyond colonialism. It refers to issues of power, rather than time. It concerns itself with concepts of race, racialization, and culture as they pertain to sociopolitical contexts and shape contemporary social life, including relations in health care (Browne, Smye, & Varcoe, 2005).

Quality of Life is the product of the interplay between social, health, economic and environmental conditions which affect human and social development. It is a broad-ranging concept, incorporating a person's physical health, psychological state, level of independence, social relationships, personal beliefs and relationship to salient features in the environment. As people age, their quality of life is largely determined by their

ability to access needed resources and maintain autonomy and independence (World Health Organization, 2004).

Role participation has been defined as “involving broad patterns of purposeful behavior at the level of societal involvement. Roles consist of acts and tasks, but because of their range and diversity, cannot be constrained to a universal list of these acts and tasks. Instead, they are dependent upon context and their assessment is largely subjective” (Gignac et al., 2008, p. 1656).

Appendices

Appendix 1. Modified Health Assessment Questionnaire

Patient Arthritis Assessment Questionnaire (PAQ)

Name _____ Date _____

The questions below concern your daily activity at this time. Please try to answer each question even if you do not feel it is related to you or any condition you may have. **There are no right or wrong answers.**

1. Please check (✓) the one best answer for your abilities at this time:

At this moment, are you able to :	without ANY difficulty	with SOME difficulty	with MUCH difficulty	UNABLE to do
a. Dress yourself, including tying shoelaces and doing buttons?	0	1	2	3
b. Get in and out of bed?	0	1	2	3
c. Lift a full cup or glass to your mouth?	0	1	2	3
d. Walk outdoors on flat ground?	0	1	2	3
e. Wash and dry your entire body?	0	1	2	3
f. Bend down to pick up clothing from the floor?	0	1	2	3
g. Turn regular faucets on and off?	0	1	2	3
h. Get in and out of a car, bus, train or airplane?	0	1	2	3

2. When you get up in the morning do you feel stiff? Yes No

If you answered Yes, please enter how many minutes or hours (approximately) it will take until you are as good as you will be for that day? _____ hours _____ minutes

3. Which of the following best describes you today? (Please check (✓) only one):

- 1: I can do everything I want to do
 2: I can do most of the things I want to do, but have some limitations
 3: I can do some, but not all, of the things I want to do, and I have many limitations
 4: I can hardly do any of the things I want to do

4. How do you feel today compared to one month ago? (Please check (✓) only one):

- 1: Much better today than one month ago
 2: Better today than one month ago
 3: Same today as one month ago
 4: Worse today than one month ago
 5: Much worse today than one month ago

5. How satisfied are you with your ability to do your usual activities? (Please check (✓) only one):

- 1: Very Satisfied
 2: Somewhat Satisfied
 3: Somewhat Dissatisfied
 4: Very Dissatisfied

6. How much pain have you had because of your condition **IN THE PAST WEEK?**

Place a vertical mark on the line below to indicate how severe your pain has been:

NO PAIN |-----| PAIN AS BAD AS IT COULD BE

7. Considering all the ways your arthritis affects you, place a vertical mark on the scale for how well you are doing.

DISEASE NOT ACTIVE |-----| SEVERE ACTIVITY

8. How much of a problem has UNUSUAL fatigue or tiredness been for you **OVER THE PAST WEEK?**

Place a vertical mark on the line below:

FATIGUE IS NO PROBLEM |-----| FATIGUE IS A MAJOR PROBLEM

REMARKS _____

Appendix 2. Outcome Measures used in Rheumatoid Arthritis

Construct	Instrument	Reference	Content	Reliability	Validity
Disease activity	Steinbrocker Therapeutic Scorecard Rheumatoid Arthritis-specific	(Steinbrocker & Blazer, 1946)	MD-completed ⁵ ; 9 items: joint swelling, joint motion, joint tenderness, ESR, Hg, weight, pain, well-being, function. Looked at impact of arthritis on occupation.	Not available in its entirety Test-retest of tender joint count kw 0.82, ICC 0.49 (Hernandez-Cruz & Cardiel, 1998) Test-retest of swollen joint count kw 0.7, ICC 0.47 (Hernandez-Cruz & Cardiel, 1998)	Construct validity between functional class with text format of RADAR Spearman's CC R=0.41; with mannequin format of RADAR R= 0.46; and with MD joint count R= 0.56 (Calvo et al., 1999)
	Lansbury Index Rheumatoid Arthritis-specific	(Lansbury, 1958)	MD-completed; Systemic index: a.m. stiffness, a.m. fatigue, pain control, grip strength, ESR. Weighted articular Index re joint involvement (tenderness & circumference): greater weight	Poor patient differentiation of pain from stiffness (Bellamy, 1989). Variable retest reliability of grip strength (Bellamy, 1989) Poor inter-tester reliability of Joint circumference (Bellamy, 1989)	Variable validity of duration of a.m. stiffness; good correlation between grip strength & upper limb function; weighted joint index correlated with CRP ; poor correlation of joint circumference (Bellamy, 1989)

⁵ Completed by physician

Construct	Instrument	Reference	Content	Reliability	Validity
			given to larger joints		
	Ritchie Index Rheumatoid Arthritis-specific	(Ritchie et al., 1968)	MD-completed; Grades joint tenderness in 15 joints of the limbs, TMJ & neck	Inter-tester reliability $\chi = .008-.148$ (Bellamy, 1989); Test-retest kw 0.83, ICC 0.49 (Hernandez-Cruz & Cardiel, 1998)	R=.89 with Index of Cooperating Clinics Committee of ARA
	Rapid Assessment of Disease Activity in Rheumatology (RADAR) Rheumatoid Arthritis-specific	(Mason et al., 1992)	Self-report; Joint pain/tenderness & clinical status, incl pain, stiffness & function today & previous 6 mos; 0-3 scale, ~10 mins to complete	ICC = 0.52 – 0.87 (p=0.0001) (83% ≥ 0.65); ICC =0.83 (p=0.0001) over 6 months; Reliability between text & mannequin format R=0.94 (Calvo et al., 1999)	R=0.74 with VAS-pain; R=0.74 – 0.81 with DAS; R=0.63 – 0.66 with function scores; R=0.53 (p<0.01) with a.m. stiffness;
	ACR Core Data Set Rheumatoid Arthritis-specific	(Felson et al., 1993)	MD- & client-completed; 7 measures: tender joint count, swollen joint count, patient's assessment of pain, PGA, MDGA, patient's assessment of physical function, & 1 acute-phase		All measures have content validity, and all are at least moderately sensitive to change, ie discriminant validity. Many of them predict other important long-term outcomes in RA, including physical disability, radiographic damage, & death.

Construct	Instrument	Reference	Content	Reliability	Validity
			reactant (ESR or CRP)		
	Disease Activity Score (DAS) Rheumatoid Arthritis-specific	(van der Heijde et al., 1993)	MD- & client-completed; swollen joints, tender joints, ESR (or CRP), PGA	Test-retest correlation = .89 Test-retest kw 0.79, ICC 0.49 (Hernandez-Cruz & Cardiel, 1998)	Factor analysis resulted in 5-factor model; cum % of explained variance 66%; Validated against X-ray findings;
	Paulus Criteria Rheumatoid Arthritis-specific	(Paulus, Egger, Ward, & Williams, 1990; Paulus & Bulpitt, 1995)	MD- & client-completed; 6 measures: a.m. stiffness, ESR, joint pain/tenderness score, joint swelling score, PGA, MDGA		
	Modified Disease Activity Score (Modified DAS-28) Rheumatoid Arthritis-specific	(Prevo et al., 1995)	MD- & client-completed; Tenderness and/or swelling of 28 joint; PGA; ESR	Canonical correlation = 0.81-0.82; Test-retest reliability Spearman's r=0.85, ICC=0.85 (Uhlig et al., 2009)	Pearson CC = 0.38 with HAQ; -0.29 - (-) 0.34 with grip strength; 0.47 – 0.53 with radiographic damage; Correlation with SDAI r=0.89; with RADAI r=0.71; (Uhlig et al., 2009)
	Rheumatoid Arthritis Disease Activity Index (RADAI)	(Stucki et al., 1995)	Self-report; Arthritis activity over 6 months;	Cronbach's α = .91; Test-retest reliability Spearman's r=0.89,	Spearman's Rank CC= R=.54 with MD assm't; r=.54 with swollen joint count;

Construct	Instrument	Reference	Content	Reliability	Validity
	Rheumatoid Arthritis-specific		today; pain today; a.m. stiffness today	ICC=0.92 (Uhlig et al., 2009)	r=.43 with CRP; r=.57 with HAQ; Correlation with DAS28 r=0.72; with SDAI r=0.80 (Uhlig et al., 2009)
	Simplified Disease Activity Index (SDAI) Rheumatoid Arthritis-specific	(Smolen et al., 2003)	MD- & client-completed; Tender & swollen 28-jt count; PGA; MDGA; CRP or ESR	Test-retest reliability Spearman's r=0.87, ICC=0.88 (Uhlig et al., 2009)	High correlation with HAQ scores (r=0.56, p<0.0001) & DAS 28 scores (r=0.91, p<0.0001); Correlation with DAS28 r=0.88; with RADAI r=0.74 (Uhlig et al., 2009)
	Swelling Articular Index Diagram Rheumatoid Arthritis-specific	(Stucki, Stucki, Bruhlmann, Maus, & Michel, 1995)	Self-report; Mannequin diagram representing 38 limb joints	Test-retest ICC = 0.63; Reliability of each joint kappa = 0.05 (0.2 with MTPs removed) - 0.72	Short (omission of toe joints) and weighted SAI diagram correlation with MD assm't ICC = .49 with CRP r= .49 with ESR r= .41
	Early Inflammatory Arthritis (EIA) Detection tool Arthritis-specific	(Bell et al., 2010)	Self-report; 12 questions re joint pain, swelling, stiffness, duration, active joints, function, diagnostic & family history	sensitivity 0.855 (SE 0.005); specificity 0.873 (SE 0.003); (Tavares et al., 2013)	Predictive validity 0.915 (SE 0.002) (Tavares et al., 2013)

Construct	Instrument	Reference	Content	Reliability	Validity
Quality of Life ⁶	Sickness Impact Profile (SIP) generic	(Bergner, Bobbitt, Pollard, Martin, & Gilson, 1976)	Completed by HCP; 14 categories incl social, mobility, sleep, nutrition, work, household, communication leisure, cognitive, emotions and hygiene	Test-retest reliability .88-.92; internal consistency .81-.97 (Bowling, 1997)	Discriminates between patient populations; $r=.49$ between SIP score & clinician assm't of dysfunction; $r= .46$ between SIP &Katz ADL score
	Arthritis Impact Measurement Scales (AIMS) Arthritis-specific	(Meenan, Gertman, & Mason, 1980)	Self-report; 45 items on 9 scales; measure physical, emotional & social well-being: mobility, physical activity, social activity, social role, ADLs, pain, dexterity, anxiety, depression; 20-30 mins to complete; complicated scoring	Guttman CR = 0.88 – 0.94; Likert coefficient = 0.70 – 0.88 Cronbach's $\alpha > .6$ for AIMS Cronbach's $\alpha = .72-.91$ in RA	Performance weakly correlated with age ($r = .12 - .49$), & all 9 scales correlated with patient perceptions of general health ($r=.35-.56$) & disease activity ($r=.27-.68$).
	Nottingham Health Profile (NHP)	(Hunt et al., 1980)	Self-report; Physical, psychological, social, role, &	Cronbach's $\alpha = 0.68-0.87$; test-re-test (4 week), part I $\alpha=0.75-0.88$;	

Construct	Instrument	Reference	Content	Reliability	Validity
	generic		sexual functioning; pain; energy.	part II α 0.55-0.89 (Frytak, 2000)	
	Stanford Health Assessment Questionnaire (HAQ) Rheumatoid Arthritis- specific	(Fries et al., 1980)	Self-report; Covers 5 domains: death; function (8 ADLs, physical & psychological, incl sexual activity & 1 IADL); discomfort; drug toxicity; economic costs. 4-point response to 24 questions; a few mins to complete & score	Spearman's CC between rater & self-administration .56-.85 .22 improvement is "clinically meaningful" (Felson, 1995)	CCs with performance .47- .88; CC with AIMS = .91; Questionable sensitivity over time (Wolfe, 2000); More valid than SF-12 in describing health status in Rheumatoid Arthritis (Linde et al., 2009) HAQ better than MHAQ at detecting treatment change & disability (Wolfe, 2001)
	McMaster Health Index Questionnaire (MHIQ) Rheumatoid Arthritis- specific	(Chambers et al., 1982)	Self-report; 3 indices: physical emotional and social functions. 20 mins to complete	Test-re-test ICC after 1 week= 0.53 (physical) 0.7 (emotional) 0.48 (social) functional indices; internal consistency co-efficients 0.76 (physical), 0.67(emotional), 0.51 (social)	MHIQ physical function index correlated with MD global physical function & VAS-pain for rest and walking on the flat;
	Medical Outcomes Study 36-item Short- Form Health Survey (SF-36)	(Ware & Sherbourne, 1992)	Self-report; 36 items covering 8 concepts: physical, role, social, & mental,	Reliability co-efficients .81- .88 (Stewart, Hays, & Ware, 1988);	92% of scales passed Item- discriminant validity; ceiling effects for role disability & social functioning scales (McHorney et al., 1994)

Construct	Instrument	Reference	Content	Reliability	Validity
	generic		functioning, pain, & health perception; ~10 mins to complete	Reliability co-efficients .65-.94 (median .85) (McHorney, Ware, Lu, & Sherbourne, 1994)	
	Arthritis Impact Measurement Scales 2 (AIMS2) Arthritis-specific	(Meenan, Mason, Anderson, Guccione, & Kazis, 1992)	Self-report; 12 scales: Addition of arm function, work & social support to original scale items	ICC r=.72-.91; test-retest reliability r=.78-.94	Significant association with patient perceived problem.
	Rheumatoid Arthritis Quality of Life (RAQoL) Rheumatoid Arthritis-specific	(de Jong, van der Heijde, McKenna, & Whalley, 1997)	Self-report; 30 items, yes/no response; 5-6 mins to complete; incl mobility, energy, pain, emotions, social isolation, physical contact & sleep	Test-re-test reliability after 2 wks Spearmans's r=.9-.94.; Cronbach's α = .92-.94	Spearmans's r=.59-.87 with NHP section score Pearson's r=.72-.75 with HAQ; -.31- -.55 with grip strength; .46-.52 with pain VAS (Tijhuis et al., 2001)
Pain	Visual Analogue Pain Rating Scale generic	(Huskisson, 1974)	MD- & client-completed; 10 cm long straight line, with verbal anchors; Vertical or horizontal	Test-retest ICC for vertical line = 0.742 (Rohekar & Pope, 2009); Retest reliability .94 in literate groups; .71 in non-literate (Ferraz et al., 1990)	Unclear (Bellamy, 1989)

Construct	Instrument	Reference	Content	Reliability	Validity
	McGill Pain Questionnaire generic	(Melzack, 1975)	MD-completed; Sensory, affective & evaluative components: pain rating index, number of words chosen & present pain intensity; 5-15 mins to complete	Intercorrelations between rank and scale values of index >0.9 Test-retest reliability weak to mod good (Bowling, 1997)	
	Arthritis Impact Measurement Scales (AIMS) Arthritis-specific	(Meenan, Gertman, & Mason, 1980)	Self-report; 45 items in 9 scales: mobility, walking/bending, hand function, self-care, household tasks, arthritis pain, tension, mood; 20-30 mins to complete; complicated scoring	Guttman coefficients of scalability > .6 & reproducibility >.9 (McDowell, 2006) Test-retest correlations >.8 after 2 weeks	Correlated with disease activity & with ARA functional class (McDowell, 2006)
	Nottingham Health Profile (NHP) generic	(Hunt et al., 1980)	Self-report; Physical, psychological, social, role, & sexual functioning; pain; energy.	Cronbach's α = 0.68-0.87; test-re-test (4 week), part I α =0.75-0.88; part II α 0.55-0.89 (Frytak, 2000)	Floor effect (Carr et al., 1996)

Construct	Instrument	Reference	Content	Reliability	Validity
	Pain Numerical Rating Scale generic	(Ferraz et al., 1990)	Self-report; 10 point scale	Retest reliability .963 in literate groups; .947 in non literate	Pain Numerical Rating Scale generic
	Pain Verbal Rating Scale generic	(Ferraz et al., 1990)	Self-report; Verbal descriptors	Retest reliability .901 in literate groups; .82 in non literate	Pain Verbal Rating Scale generic
	Pain Articular Index List Rheumatoid Arthritis-specific	(Stucki, Stucki, Bruhlmann, Maus, & Michel, 1995)	Self-report; List of 16 limb joints	Test-retest ICC = 0.85; Reliability of each joint kappa = 0.52-0.72	PAI list correlation With MD assm't r= .49 ; With HAQ r=.49 With CRP r=.37; With AM stiffness r= .52
	Pain Articular Index Diagram Rheumatoid Arthritis-specific	(Stucki et al., 1995)	Self-report; Mannequin diagram representing 42 limb joints	Test-retest ICC = 0.67; Reliability of each joint kappa = 0.03 (0.33 with MTPs removed) - 0.77	PAI diagram correlation With MD assm't r= .49 ; With HAQ r=.30; With CRP r=-.04; With AM stiffness r= .32
	Rheumatoid Arthritis Pain Scale (RAPS) Rheumatoid Arthritis-specific	(Anderson, 2001)	Self-report; 24 questions on 4 dimensions: physiological, affective, sensory & cognitive; 7-pt rating response	Internal consistency for overall RAPS Cronbach's α = .92; for 4 subscales Cronbach's α = .65-.86;	Construct: exploratory factor analysis yielded 3 factors; Criterion: Pearson's CC with total joint count r=0.52; with modified VAS r=0.68

Construct	Instrument	Reference	Content	Reliability	Validity
Activity and/or participation	Katz Index of ADL generic	(Katz et al., 1963)	Completed by HCP ⁶ ; 3-point scale: ability to bathe, dress, toilet, transfer, feed self, control bowel & bladder.	Scale reliability 0.56; CR =0.94-0.97 (Pearson, 2000)	Correlated with house confinement (r=.39) and mobility (r=.5) (Katz, Downs, Cash, & Grotz, 1970)
	Barthel Index generic	(Mahoney & Barthel, 1965)	Completed by HCP; 10-item scale: ability to feed self, groom, control bowel & bladder, dress, toilet, transfer, walk, stairs, & bathe	Inter-rater= 0.88 - 0.99 (McDowell, 2006); α = 0.95 - 0.96 (Pearson, 2000) (Finch, Brooks, Stratford, & Mayo, 2002)	Low scores correlated with increased mortality (McDowell, 2006) Ceiling effects ⁶ limits use in in-patients (Wright, Cross, & Lamb, 1998)
	Lawton Instrumental Activities of Daily Living (IADL) scale generic	(Lawton & Brody, 1969)	Completed by HCP; Use of phone, housekeeping, food prep, laundry, transportation, meds, money mg't.	Inter-rater= 0.85; CR=0.96 for men; 0.93 for women (Pearson, 2000)	Correlations with ADLs 0.77; Mental status 0.74; physical health 0.5
	Index of Social Function generic	(Chambers et al., 1976)	Completed by HCP; 14 items, incl social visits & outings,	test-re-test reliability Goodman-Kruskal Index of .9 (SE 0.05)	Compared to clinical assessment of social functioning, sensitivity = 72%; specificity = 77%; "Good" PV= 97%; "poor" PV = 20%

⁶ Health Care Provider (HCP)

Construct	Instrument	Reference	Content	Reliability	Validity
	Sickness Impact Profile (SIP) generic	(Bergner, Bobbitt, Pollard, Martin, & Gilson, 1976)	Completed by HCP; 14 categories incl social, mobility, sleep, nutrition, work, household, communication leisure, cognitive, emotions and hygiene	Test-retest reliability .88-.92; internal consistency .81-.97 (Bowling, 1997)	Discriminates between patient populations; $r=.49$ between SIP score & clinician assm't of dysfunction; $r= .46$ between SIP &Katz ADL score
	Stanford Health Assessment Questionnaire (HAQ) Rheumatoid Arthritis-specific	(Fries et al., 1980)	Self-report; Covers 5 domains: death; function (8 ADLs, physical & psychological, incl sexual activity & 1 IADL); discomfort; drug toxicity; economic costs. 4-point response to 24 questions; a few mins to complete & score	Spearman's CC between rater & self-administration .56-.85 .22 improvement is "clinically meaningful" (Felson, 1995)	CCs with performance .47-.88; CC with AIMS = .91; Questionable sensitivity over time (Wolfe, 2000); More valid than SF-12 in describing health status in Rheumatoid Arthritis (Linde et al., 2009) HAQ better than MHAQ at detecting treatment change & disability (Wolfe, 2001)
	Stanford Health Assessment Questionnaire Disability Index (HAQ-DI)	(Fries et al., 1980; Fries et al., 1982)	Self-report; 20 questions on 8 ADL in previous week, rated 0-3: Dressing/grooming, arising, eating,	Test-retest ICC = 0.897 (Rohekar & Pope, 2009) Spearman CC = 0.85	Correlations with performance = .71-.95 (criterion validity) (Bruce & Fries, 2003); Responsiveness supported by effect size over 12 mos

Construct	Instrument	Reference	Content	Reliability	Validity
	Rheumatoid Arthritis-specific		walking, hygiene, reach, grip, outdoor activities		(0.63-0.75) (Amjadi et al., 2009) Predicts work disability (Lubeck, 2002)
	Arthritis Impact Measurement Scales (AIMS) Arthritis-specific	(Meenan, Gertman, & Mason, 1980)	Self-report; 45 items in 9 scales: mobility, walking/bending, hand function, self-care, household tasks, arthritis pain, tension, mood; 20-30 mins to complete; complicated scoring	Guttman coefficients of scalability > .6 & reproducibility >.9 (McDowell, 2006) Test-retest correlations >.8 after 2 weeks	Correlated with disease activity & with ARA functional class (McDowell, 2006)
	Functional Status Index Rheumatoid Arthritis-specific	(Jette, 1980; Jette, 1987)	Self-report; Measures degree of pain, difficulty, and dependence in 18 ADLs (gross mobility, home chores, hand activities, personal care, social/role activities)	Spearman CC = 0.66 – 0.91 for 4; 0.23 – 0.547 for hand; Test-re-test and inter-tester reliability = 0.65 – 0.81	Convergent validity assessed by correlating with ARA classification, professional global assm't of function & disease activity: Pearson product moment correlation 0.25-0.49; Concurrent validity assessed against observed functional performance r= 0.71-0.95; Good correlation with HAQ (Bowling, 1997)

Construct	Instrument	Reference	Content	Reliability	Validity
	Older Americans' Resources and Services (OARS) Multidimensional Functional Assessment Questionnaire generic	(Fillenbaum & Smyer, 1981)	Completed by HCP; 5 dimensions: social, economic, mental health, physical health, & self-care; 6-pt scale	ICC = .66-.87	Criterion validity Kendall's Tau=.6-.89 for 4 dimensions (excl social)
	Modified Health Assessment Questionnaire (MHAQ) Rheumatoid Arthritis-specific	(Pincus et al., 1983)	Self-report; Incl 8 ADL; patient's perceived satisfaction with ADL; perceived change in degree of difficulty; VAS for pain, fatigue & GI distress	α coefficients all high ($p < 0.001$); test-retest $r = 0.911$ after 1 month (Pincus, et al., 1983) Less sensitive than full HAQ (Wolfe, 2001)	Concurrent validity assessed against HAQ Pearson's $r = 0.54-0.84$ Principal component factor analysis comparing MHQ to HAQ highly correlated ($p < 0.001$) (Pincus et al., 1983)
	McMaster Toronto Arthritis (MACTAR) Patient Preference Disability Questionnaire Rheumatoid Arthritis-specific	(Tugwell et al., 1987)	Self-report; Functional priorities of patients, using interview questionnaire; Requires trained interviewers; ~15 mins to complete	unavailable	48% of items covered by HAQ; valid and responsive (Verhoeven et al., 2000)

Construct	Instrument	Reference	Content	Reliability	Validity
	Arthritis Impact Measurement Scales 2 (AIMS2) Arthritis-specific	(Meenan, Mason, Anderson, Guccione, & Kazis, 1992)	Self-report; 12 scales incl mobility, walking/bending, hand function, self-care, household tasks, arthritis pain, tension, mood, arm function, work & social support	Internal consistency coefficients (Cronbach's α) 0.72-0.91; Test-re-test reliability (ICC) after 2-3 weeks 0.78-0.94	Validated with subjects' health problem(s) and priority for improvements
	Multidimensional Health Assessment Questionnaire (MDHAQ) Rheumatoid Arthritis-specific	(Pincus et al., 1999)	Self-report; 8 MHAQ items + 6 advanced ADL + 4 psychological (depression, anxiety, sleep, stress) = 18 items	Test-re-test reliability after 5 weeks kappa statistic = .65-.81	Spearman's rho C for 4 psychological items = .5-.75 with other scales (MHAQ, VAS – pain & fatigue, RAI, AIMS-anxiety & depression, BDI)
	International Classification of Functioning, Disability and Health (ICF) Core Set for Rheumatoid Arthritis Rheumatoid Arthritis-specific	(Stucki & Cieza, 2004; Stucki et al., 2004)	Completed by HCP & client; 96 categories in comprehensive core set; 39 in brief core set, incl body functions, body structures, activities & participation & environmental factors		Developed through consensus project involving 17 experts from 12 countries; Content validation by qualitative means (focus groups of persons with RA) ; Moderate responsiveness in scores to treatment (Coenen et al., 2006; Uhlig et al., 2009)

Construct	Instrument	Reference	Content	Reliability	Validity
	Rheumatology Function Tests Rheumatoid Arthritis-specific	(Escalante, Haas, & del Rincón, 2004)	Completed by HCP; Grip strength, walking speed, timed shirt button speed	Intra-observer variability of grip strength using a blood measure cuff is 10 mm/Hg; inter-observer variability 20 mm/Hg (Bellamy, 1989)	Good correlation of grip strength with Ritchie Index & upper limb function; poor responsiveness of timed 50 ft walking test (Bellamy, 1989)
	Recent-Onset Arthritis Disability Index (ROAD) Rheumatoid Arthritis-specific	(Salaffi et al., 2005)	Self-report; 12 items: 5 upper limb function; 4 lower limb function; & 3 ADL/work	Test-retest ICC .85-.93 Bland & Altman plot confirmation	Construct Spearman's CCs Rho=.372 with HAQ; rho=-.413 with PCS of SF36; rho=.417 with PGA func dis; rho= .639 with pain. Responsiveness tested with effect size; response mean; ROC curve analysis
	Measure of Activity Limitation (MAL) Rheumatoid Arthritis-specific	(Goodacre et al., 2007)	Self-report; 36 items re impact of symptoms on activity, global function, & task performance	Two week test-re-test reliability ICC 0.95	R=0.73 with HAQ; r=-0.74 with physical function scale of SF36; face & content validity assessed with qualitative interviews
	Valued Life Activity (VLA) Scale	(Katz, Morris & Yelin, 2006)	Self-report; 26 life activities including obligatory, committed & discretionary.		Age, gender & disease duration predictable of VLA score (R^2 0.28-0.47).

Construct	Instrument	Reference	Content	Reliability	Validity
			4-point scale of difficulty; excludes irrelevant activities.		
	World Health Organization Disability Assessment Scale 2.0 (WHODAS II) generic	(Üstün, T. B., Kostanjsek, N., Chatterji, S., & Rehm, J. (Eds.) (2010).	Self-report or administered; 36-item or 12-item; 6 domains: cognition, mobility, self-care; interactions; life activities; & participation.	Cronbach's alpha 0.86-0.95; test-retest ICC 0.82-0.96 (Gignac, Cao, McAlpine & Badley, 2011)	criterion, construct, & discriminant good to excellent; ongoing tests of predictive validity & sensitivity to change (Gignac, Cao, McAlpine & Badley, 2011)
Other	Medical Outcomes Study 36-item Short-Form Health Survey (SF-36) generic	(Ware & Sherbourne, 1992)	Self-report; 36 items covering 8 concepts: physical, role, social, & mental, functioning, pain, & health perception; ~10 mins to complete	Reliability co-efficients .81-.88 (Stewart et al., 1988); Reliability co-efficients .65-.94 (median .85) (McHorney et al., 1994)	92% of scales passed Item-discriminant validity; ceiling effects for role disability & social functioning scales (McHorney et al., 1994)
	Physician global assessment (MDGA)	(Rohekar & Pope, 2009)	MD-completed; 10 cm horizontal line without intervals & anchors; one	Test-retest ICC = 0.961; Test-retest kw 0.79, ICC 0.48 (Hernandez-Cruz & Cardiel, 1998);	Correlation with PGA = - 0.172; Correlation with DAS28 r=0.78; with RADAI r=0.49

Construct	Instrument	Reference	Content	Reliability	Validity
	Rheumatoid Arthritis-specific		question re overall rating of arthritis on that given day	Test-retest reliability Spearman's $r=0.69$, ICC=0.79 (Uhlig et al., 2009)	(Uhlig et al., 2009)
	Patient global assessment (PGA) Rheumatoid Arthritis-specific	(Rohekar & Pope, 2009)	Self-report; 10 cm horizontal line with intervals & anchors; one question re overall health	Test-retest ICC = 0.702; Test-retest kw 0.58, ICC 0.48 (Hernandez-Cruz & Cardiel, 1998) Spearman rank-order correlation = 0.92, ICC=0.93 (Pincus et al., 2008)	Correlation with MDGA = - 0.172; Correlation with RADAI $r=0.80$ (Uhlig et al., 2009)
	VAS – fatigue Rheumatoid Arthritis-specific	(Rohekar & Pope, 2009)	Self-report of level of fatigue over the previous week; 10 cm horizontal line with intervals & anchors	Test-retest ICC = 0.741	
	VAS - sleep Rheumatoid Arthritis-specific	(Rohekar & Pope, 2009)	Self-report of sleeping over the previous week; 10 cm horizontal line with intervals & anchors	Test-retest ICC = 0.8	

Appendix 3. Factor Analysis for MHAQ, all data combined

Correlation Matrix^a

		HAQ_Dress _Rating	HAQ_Rise _Rating	HAQ_Eat_ Rating	HAQ_Walk_ Rating	HAQ_Hygiene _Rating	HAQ_Reach _Rating	HAQ_Grip _Rating	HAQ_Activity _Rating
Correlation	HAQ_Dress_Rating	1.000	.580	.540	.567	.671	.591	.560	.611
	HAQ_Rise_Rating	.580	1.000	.487	.541	.561	.589	.466	.619
	HAQ_Eat_Rating	.540	.487	1.000	.472	.580	.474	.583	.526
	HAQ_Walk_Rating	.567	.541	.472	1.000	.592	.589	.425	.637
	HAQ_Hygiene_Rating	.671	.561	.580	.592	1.000	.604	.552	.617
	HAQ_Reach_Rating	.591	.589	.474	.589	.604	1.000	.482	.685
	HAQ_Grip_Rating	.560	.466	.583	.425	.552	.482	1.000	.549
	HAQ_Activity_Rating	.611	.619	.526	.637	.617	.685	.549	1.000
Sig. (1-tailed)	HAQ_Dress_Rating		.000	.000	.000	.000	.000	.000	.000
	HAQ_Rise_Rating	.000		.000	.000	.000	.000	.000	.000
	HAQ_Eat_Rating	.000	.000		.000	.000	.000	.000	.000
	HAQ_Walk_Rating	.000	.000	.000		.000	.000	.000	.000
	HAQ_Hygiene_Rating	.000	.000	.000	.000		.000	.000	.000
	HAQ_Reach_Rating	.000	.000	.000	.000	.000		.000	.000
	HAQ_Grip_Rating	.000	.000	.000	.000	.000	.000		.000
	HAQ_Activity_Rating	.000	.000	.000	.000	.000	.000	.000	

a. Determinant = .011

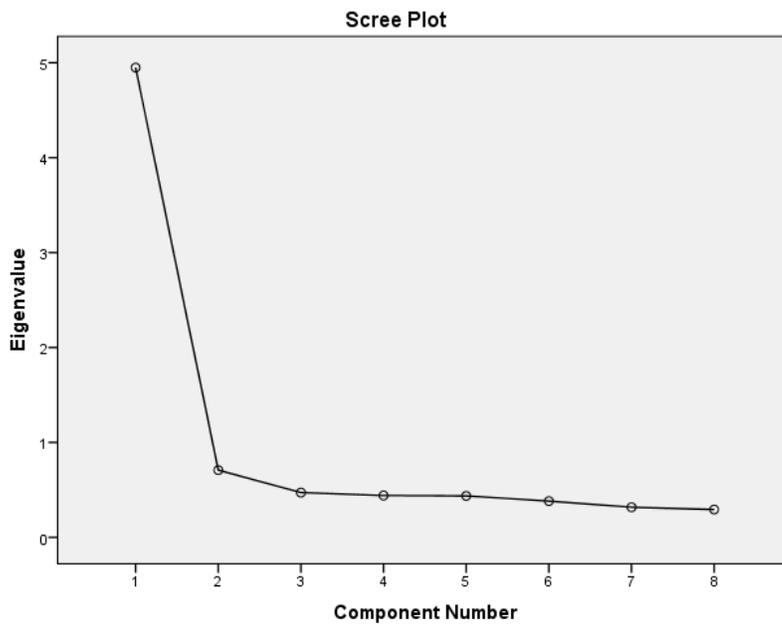
KMO and Bartlett's Test

Kaiser-Meyer-Olkin Measure of Sampling Adequacy.		.931
Bartlett's Test of Sphericity	Approx. Chi-Square	3943.534
	df	28
	Sig.	.000

Total Variance Explained

Component	Initial Eigenvalues			Extraction Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	4.949	61.861	61.861	4.949	61.861	61.861
2	.708	8.853	70.714			
3	.472	5.895	76.609			
4	.441	5.510	82.119			
5	.437	5.464	87.583			
6	.382	4.780	92.363			
7	.318	3.970	96.332			
8	.293	3.668	100.000			

Extraction Method: Principal Component Analysis.



Appendix 4. Qualitative Interview Guide

1. Can we please start by you telling me a little about yourself.
2. Can you now tell me a little about your joint disease; when did you first start having problems with your joints; when were you first seen by a rheumatologist; and when were you first diagnosed with RA?
3. Can you tell me how arthritis has had an impact on your life?
Probing questions:
 - a. What are the sorts of things you do on an everyday basis that you have the most difficulty with because of your joints?
 - b. Is there anything you had to stop doing because of your arthritis?
 - c. How has your joint disease changed what you do out and about in your community? Either at work, at home or in your community. How so?
 - d. Many people with Rheumatoid Arthritis say that the joint disease has affected their relationships with other people and how they interact with those other individuals. Can you describe how arthritis has impacted any of your own relationships? With your children, your spouse, your parents, or your relatives? Or with your boss or co-workers?
4. You filled out a questionnaire today about how you are functioning with your joint disease. I'd like to go through those questions together with you now.
(review MHAQ item by item)
Probing questions:
 - a. Have you ever filled out this questionnaire before today? Did you have any difficulty with understanding what they were asking?
 - b. How do you actually do the thing the question asks you?
 - c. Do you need help to do that task normally? What kind of help?
 - d. *(Where more than 1 answer is given or answer is missing)* Tell me why you answered this question the way you did; or why you left it blank.
5. At the bottom of the page the questionnaire asks you to mark a line to show where you are at in the past week in terms of pain, disease activity and fatigue. How did you decide where to mark the line?
 - a. *(if relevant)* I see that you left it blank. Can you tell me why you didn't you fill that in?
6. Are there any other types of activities that you wish were on this list? Anything from work, church, or community events or traditional activities?
7. How do you think what you filled in on this piece of paper affects the care you receive?
8. Do you have any suggestions to your doctor or nurse or other health care provider on how care to First Nations people with arthritis could be improved?
9. Do you have anything else you want to add or want to talk about in terms of living with arthritis?

Appendix 5. Participant Consent



**UNIVERSITY
OF MANITOBA** | Faculty of Medicine

Department of
Community Health Sciences,
750 Bannatyne Avenue
Winnipeg, Manitoba
Canada R3E 0W3
Fax (204) 789-3905

Research Participant (Client) Information and Consent Form

Title of Study: Validation of the Modified Health Assessment Questionnaire in First Nations persons with Rheumatoid Arthritis

Principal Investigator: Moni Fricke
University of Manitoba
R160-771 McDermot Avenue
Winnipeg
Tel 204.789.3814

Sponsor: Department of Community Health Sciences

You are being asked to participate in a research study. Please take your time to review this consent form and discuss any questions you may have with the study staff. You may take your time to make your decision about participating in this study and you may discuss it with your friends, family or (if applicable) your doctor or nurse before you make your decision. This consent form may contain words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand.

Purpose of Study

This research study is being conducted to study the perspectives and experiences of First Nation persons living with Rheumatoid Arthritis. The purpose of this study to determine whether or not the surveys used to measure disability in Rheumatoid Arthritis are accurate and truly reflect your experience living with Rheumatoid Arthritis. A total of 35 participants will participate in this study.

Study procedures

This is a two-part study, in which your participation is requested for the second phase. The first phase is examining existing clinical data or numbers. In the second phase, persons who self-identify as First Nations will complete a questionnaire about his or her ability to function at home, levels of joint pain and fatigue. The questionnaire takes approximately 5-10 minutes to complete and is part of your routine medical follow-up. After that, you will be asked a series of questions about the actual questionnaire you just completed and about living with Rheumatoid Arthritis in your community. The questions will focus on your understanding of the questions, their relevance to your daily life, and what meaning or value this questionnaire may or may not have for you.

The interview will last 90-120 minutes and will take place in a location agreed upon by both you and the researcher. Interviews will be tape recorded and typed out word for word; interpreters will be available as needed. All participants will be asked to review a summary of the combined findings at a later date for accuracy; no participants will be identified by name in the summary.

An additional component of this phase of the study will be interviews with health care providers about their use of such questionnaires, that is, why and how they use the information gathered in the questionnaire.

If you take part in this study, you will be asked the following types of questions:

What are the sorts of things you do on an everyday basis that you have the most difficulty with because of your joints? Is there anything you had to stop doing completely because of your joints?

Can you actually do the thing they ask you as listed in the questionnaire?

Do you actually do that at home? Or do you need help to do that task normally?

What kind of help?

What other types of important activities in your life do you wish were on this list?

Anything from work, church, or community events? How do you get around in your community?

Participation in the study will include one interview, followed by a review approximately four to six months later of a summary of the most important findings of all interviews combined. All identities of participating individuals will be kept anonymous in this compilation, which you can have either mailed to you or provided to you by the research assistant. Your mailing address or e-mail address will be required if you choose to receive the interview summary through mail. If you wish to add something to the interview summary at that time, you can either call the researcher directly or mail it to her within a two week time frame. If you do not provide any comments on the interview summary, it will be assumed that you have no changes to make and you agree with the summary as written.

You can stop participating at any time. However, if you decide to stop participating in the study, we encourage you to talk to the study staff first. There will be no negative results should you choose not to participate.

Should you choose to participate, a copy of the overall study report summarizing all phases of the study will be provided to you for your review and comments. The identity of all participants will remain anonymous by the removal of any identifying features. If you do not provide any comments on the study report, it will be assumed that you have no changes to make and you agree with the report as written. A copy of the study report will also be provided to the St. Theresa Point Band Council, as well as all participants in the study as requested.

Risks and Discomforts

No physical risks are expected for any participants in this study. There may be some potential discomfort related to the sensitive nature of the questions.

Benefits

There may or may not be direct benefit to you from participating in this study. We hope the information learned from this study will benefit other people with Rheumatoid Arthritis in the future.

Costs

All the procedures, which will be performed as part of this study, are provided at no cost to you. The study researcher is receiving some financial support to conduct this study.

Payment for participation

For your participation, you will be given \$25.00 cash for the interview in this research study. Upon submission of your feedback of the written summary of the combined and anonymized interview results, you will be paid a further \$25.

You do not have to participate in this study to receive treatment for your condition. Please talk to your regular doctor (or therapist or nurse) about all your treatment options.

Confidentiality

Information gathered in this research study may be published or presented in public forums; however, your name and other identifying information will not be used or revealed. All study related documents will bear only a study number. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law.

The University of Manitoba Health Research Ethics Board may review records related to the study for quality assurance purposes.

All records will be kept in a locked secure area and only the primary researcher will have access to these records. Your name and all identifying information will be removed if any of your research records need to be copied to any of the above. No information revealing any personal information such as your name or address will leave the University of Manitoba. All audiotapes will be destroyed at the end of the study as per confidential waste procedures of the University of Manitoba; this is anticipated to be no later than the summer of 2014.

Voluntary Participation/Withdrawal from the Study

Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time. Your decision not to participate or to withdraw from the study will not affect your care at this centre. If the study staff feel that it is in your best interest to withdraw you from the study, they will remove you without your consent.

We will tell you about any new information that may affect your health, welfare, or willingness to stay in this study.

Questions

You are free to ask any questions that you may have about your treatment and your rights as a research participant. If any questions come up during or after the study or if you have a research-related injury, contact the researcher, Moni Fricke at (204) 789-3814.

For questions about your rights as a research participant, you may contact The University of Manitoba, Bannatyne Campus Research Ethics Board Office at (204) 789-3389.

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

Statement of Consent

I have read this consent form. I have had the opportunity to discuss this research study with Moni Fricke and or her study staff. I have had my questions answered by them in language I understand. The risks and benefits have been explained to me. I believe that I have not been unduly influenced by any study team member to participate in the research study by any statements or implied statements. Any relationship (such as employer, supervisor or family member) I may have with the study team has not affected my decision to participate. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

I understand that information regarding my personal identity will be kept confidential, but that confidentiality is not guaranteed. I authorize the inspection of any of my records that relate to this study by The University of Manitoba Research Ethics Board and/or the St. Theresa Point Band Council for quality assurance purposes.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

I agree to be contacted for future follow-up in relation to this study, Yes _ No _

Participant signature _____ Date _____
(day/month/year)

Participant printed name: _____

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent

Printed Name: _____ Date _____
(day/month/year)

Signature: _____

Role in the study: _____

Relationship (if any) to study team members: _____

Appendix 6. Letter of Permission to access UMHSAC Database



Health Sciences Centre
Winnipeg

Arthritis Centre

September 28, 2012

Hani El-Gabalawy, MD, FRCPC *
RR149-800 Sherbrook Street
Winnipeg, MB R3A 1M4

Appointments: (204) 787-2392
Office: (204) 787-2208
Fax: (204) 787-4594

* Denotes Medical Corporation

Dear University of Manitoba Human Research Ethics Board

Re: Access to UMHSAC longitudinal clinical and research database

I hereby grant permission to Monica Fricke, PhD candidate in the Department of Community Health Sciences, to access the University of Manitoba Health Sciences Arthritis Centre longitudinal clinical and research database as part of her doctoral work. I understand that she will complete a secondary data analysis of the existing data in her quest to validate the *Modified Health Assessment Questionnaire* in First Nations persons in Manitoba. All data will be kept securely stored and the confidentiality of individual entries maintained throughout. Her electronic copy of the data base will be returned to the Health Sciences Arthritis Centre upon completion of the study.

I agree with the proposed study as it supports work currently being done both clinically and in research at our centre. If you have any questions or wish to discuss this further, please feel free to contact me directly.

Sincerely,

Hani S. El-Gabalawy, MD FRCPC
Professor in Medicine and Immunology
Endowed Rheumatology Research Chair
University of Manitoba

HEG/ls

Adult Office (204) 787-1851 Appointments (204) 787-2392 Fax (204) 787-4595 / Pediatric Office (204) 787-2020 Fax (204) 787-2475
RR149, 800 Sherbrook Street, Winnipeg, Manitoba Canada R3A 1M4 www.hsc.mb.ca



Appendix 7. Letter of permission from St. Therese Band Council



ST. THERESA POINT FIRST NATION

ST. THERESA POINT, MANITOBA
R0B 1J0



Phone: (204) 462-2106
(204) 462-2145
Fax: (204) 462-2646

December 17, 2012

Moni Fricke
PhD Student
c/o School of Rehabilitation
University of Manitoba
R106-771 McDermot Avenue
Winnipeg, Manitoba
R3E 0T6

**RE: Amendment Request to Early Identification Rheumatoid Arthritis in
Canadian First Nation Communities Study**

Dear Moni Fricke;

This letter will serve as an agreement to the proposed amendment outlined in the letter dated September 28, 2012 from Dr. El-Gabalawy, to the existing and fully approved study between the University of Manitoba Arthritis Centre Clinical Research Unit and the St. Theresa Point First Nation, which was originally signed on February 26, 2007. The proposed project is consistent with the overall goals, principles, objectives and guidelines of the original agreement.

As described in the letter dated September 28, 2012 and as discussed over the telephone with the St. Theresa Point First Nation Health Councillor, Robert Flett, on December 11, 2012, the proposed project is presented as a component of the Early Identification of Rheumatoid Arthritis in Canadian First Nation Communities Study taking place in St. Theresa Point First Nation. As part of the current study, the participants complete a written questionnaire, asking about any difficulty they may or may not be having with their daily activities. The questionnaire, the Modified Health Assessment Questionnaire, has never been assessed for its accuracy in measuring the impact of arthritis on an individual from a First Nations community in Canada and whether or not the items are as meaningful to life in St. Theresa Point First Nation as elsewhere.

.../2

Page 2

Moni Fricke, PhD Student
c/o School of Medical Rehabilitation

We support in principle the assessment of the usefulness of this questionnaire by persons in our community. We understand that the researcher, Moni Fricke, from the University of Manitoba, will accompany the Rheumatologist to St. Theresa Point First Nation on community visits in 2013 and/or 2014 and meet with up to 15 individual adults with Rheumatoid Arthritis. The discussion will last 1 – 1 ½ hours each and would take place either in the nursing station or in the person's home as requested by the individual. The research assistant from our community would assist in this process, including language interpretation where indicated. Interviews will be audio-taped, subsequently typed out and analyzed for content; the identity of all individuals will be kept confidential. Each person will be asked to sign a consent form before proceeding. All audio-tapes will be destroyed at the conclusion of the project.

As in the original agreement and subsequent amendments, we anticipate receiving regular updates regarding the progress and outcome of this research. We feel this request is in keeping with the overall agreement surrounding the Early Identification of Rheumatoid Arthritis study and wish you success in this endeavor.

Sincerely,

**CHIEF & COUNCIL
ST. THERESA POINT FIRST NATION**

Chief Eugene Wood

Councillor Michael John Harper

Councillor Jack Flett

Councillor Marie A. Wood

Councillor Mary Jane Monias

Councillor Rosaire Mason

Councillor Robert Flett

Councillor Jackson Taylor

Councillor Eddy Mark Wood

c.c. Dr. H. El-Gabalawy, Arthritis Centre Clinical Research Unit, University of Manitoba

Appendix 8. Approval for study from Assembly of Manitoba Chiefs



ASSEMBLY OF MANITOBA CHIEFS SECRETARIAT INC.

2nd Floor • 275 Portage Avenue • Winnipeg, Manitoba • R3B 2B3 • Telephone: (204) 956-0610 • Fax: (204) 956-2109

October 30, 2013

Moni Fricke, BMR (PT), MSc
Department of Physical Therapy, School of Medical Rehabilitation
Faculty of Medicine
University of Manitoba
R106-771 McDermot Avenue
Winnipeg, Manitoba

Dear Ms. Fricke:

Re: Validation of the Modified Health Assessment Questionnaire in First Nations Persons with Rheumatoid Arthritis

Thank you for your submission to the Assembly of Manitoba Chiefs Health Information Governance Committee (AMC HIRGC). Your Research Application has been reviewed and the committee agreed to support your research with the following recommendations:

- In order for research to truly be a capacity building tool, there needs to be thought given to developing evidence for long term positions in health and social services. This research opportunity can support that by identifying ways for a community to maintain/sustain a person on the ground. The patients living with and seeking support for RA may require additional funds available to them through Income Assistance and the necessary assessments and re-assessments that IA policy requires needs assessments to be conducted by informed and appropriate service providers. Lack of these appropriate service providers may cause people living with RA to leave their home communities to obtain the needed supports or even assessments. Any assessment tool that looks to become more culturally appropriate in First Nations needs to take into account how leaving the home community affects the people and how a community can build a more solid evidence base to obtain the funding to bring in those services that communities currently lack.
- Any proposed presentations or publications regarding this data must be sent for review to AMC HIRGC prior to the event or publication.

If you have any further questions please contact Leanne Gillis at lgillis@manitobachiefs.com.

Miigwech

ASSEMBLY OF MANITOBA CHIEFS

Kathi Avery Kinew, M.S.W., Ph. D
Manager, Social Development & Research Initiatives

HEAD OFFICE: Swan Lake First Nation • Unit 9-4820 Portage Avenue • Headingley, MB R4H 1C8 • Telephone: (204) 956-0610

Appendix 9. University of Manitoba Human Research Ethics Board Approval



P126 - 770 Bannatyne Avenue
Winnipeg, Manitoba
Canada R3E 0W3
Tel: (204) 789-3255
Fax: (204) 789-3414

PRINCIPAL INVESTIGATOR: Ms. M. Fricke	INSTITUTION/DEPARTMENT: UofM / Community Health Sciences	ETHICS #: HS15942 (H2012:365)
HREB MEETING DATE: November 26, 2012	APPROVAL DATE: January 9, 2013	EXPIRY DATE: November 26, 2013
STUDENT PRINCIPAL INVESTIGATOR SUPERVISOR (If applicable): Dr. B. Elias		
PROTOCOL NUMBER: NA	PROJECT OR PROTOCOL TITLE: Validation of the Modified Health Assessment Questionnaire in First Nations Persons with Rheumatoid Arthritis (Linked to H2005:093)	
SPONSORING AGENCIES AND/OR COORDINATING GROUPS: Health Canada and UofM Internal Funds		
Submission Date(s) of Investigator Documents: November 8, 2012 and January 8, 2013		REB Receipt Date(s) of Documents: November 8, 2012 and January 8, 2013

THE FOLLOWING ARE APPROVED FOR USE:

Document Name	Version(if applicable)	Date
Protocol:		
Protocol		January 8, 2013
Consent and Assent Form(s):		
Research Participant (Client) Information and Consent Form		January 8, 2013
Research Participant (Healthcare Provider) Information and Consent Form		January 8, 2013
Research Participant Follow Up Contact Information		November 5, 2012
Other:		
Modified Health Assessment Questionnaire		November 5, 2012
Client Interview Draft Question Guideline		November 5, 2012
Healthcare Provider Interview Draft Question Guideline		November 5, 2012

CERTIFICATION
The University of Manitoba (UM) Health Research Board (HREB) has reviewed the research study/project named on this **Certificate of Final Approval** at the **full board meeting** date noted above and was found to be acceptable on ethical grounds for research involving human participants. The study/project and documents listed above was granted final approval by the Chair or Acting Chair, UM HREB.

HREB ATTESTATION
The University of Manitoba (UM) Health Research Board (HREB) is organized and operates according to Health Canada/ICH Good Clinical Practices, Tri-Council Policy Statement 2, and the applicable laws and regulations of Manitoba. In respect to clinical trials, the HREB complies with the membership requirements for Research Ethics Boards defined in Division 5 of the Food and Drug Regulations of Canada and carries out its functions in a manner consistent with Good Clinical Practices.

QUALITY ASSURANCE

The University of Manitoba Research Quality Management Office may request to review research documentation from this research study/project to demonstrate compliance with this approved protocol and the University of Manitoba Policy on the Ethics of Research Involving Humans.

CONDITIONS OF APPROVAL:

1. The study is acceptable on scientific and ethical grounds for the ethics of human use only. **For logistics of performing the study, approval must be sought from the relevant institution(s).**
2. This research study/project is to be conducted by the local principal investigator listed on this certificate of approval.
3. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to the research study/project, and for ensuring that the authorized research is carried out according to governing law.
4. **This approval is valid until the expiry date noted on this certificate of approval. A Bannatyne Campus Annual Study Status Report** must be submitted to the REB within 15-30 days of this expiry date.
5. Any changes of the protocol (including recruitment procedures, etc.), informed consent form(s) or documents must be reported to the HREB for consideration in advance of implementation of such changes on the **Bannatyne Campus Research Amendment Form.**
6. Adverse events and unanticipated problems must be reported to the REB as per Bannatyne Campus Research Boards Standard Operating procedures.
7. The UM HREB must be notified regarding discontinuation or study/project closure on the **Bannatyne Campus Final Study Status Report.**

Sincerely,

John, Arnett, PhD., C. Psych.
Chair, Health Research Ethics Board
Bannatyne Campus

Please quote the above Human Ethics Number on all correspondence.
Inquiries should be directed to the REB Secretary Telephone: (204) 789-3255/ Fax: (204) 789-3414

Appendix 10. Winnipeg Health Sciences Centre Approval



Health Sciences Centre
Winnipeg

Office of the Director of Research

Dial Direct 204-787-4831
Fax 204-787-4547

January 18, 2013

Ms Monica Fricke
Principal Investigator
R160-771 McDermot Avenue

Dear Ms Monica Fricke

**RE: VALIDATION OF THE MODIFIED HEALTH ASSESSMENT QUESTIONNAIRE
IN FIRST NATIONS PERSONS WITH RHEUMATOID ARTHRITIS.**

**ETHICS #: HS15942
RIC #: R12012:183**

The above-named protocol identified as *non-contract research*, **has been evaluated and approved** by the HSC Research Impact Committee Members. This study will be administered through the University of Manitoba, and will be undertaken, in whole or part, at the Health Sciences Centre.

Please ensure when completing the U of M Funding Application Approval Form, in Section 7, point b, only check off 6 (other), and indicate all premises, including HSC.

Once you received your FOP number from the U of M, please forward a copy of the number along with a copy of your Funding Application Form to Josie Villanueva, Research Department, MS748A.

Should you have any questions or concerns with the above, please call our office at 787-4968. Thank you, and best wishes with your study.

Sincerely

Karen Shaw-Allan
Research Protocol Officer

cc: Ms Nancy Klos, Office of Research Services, Assoc Dir (Research Grants), T151 Basic Science Bldg
HSC Finance Division
Josie Villanueva, HSC Research Department, Financial Analyst, MS748A

M57 - 820 Sherbrook Street, Winnipeg, Manitoba Canada R3A 1R9

www.hsc.mb.ca

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Health Authority
Office régional de la
santé de Winnipeg

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UNIVERSITY
OF MANITOBA

Appendix 11. SPSS Output of Unpaired t-tests of Disease Measures

Lab measures

Group Statistics					
	Ethnic_Code	N	Mean	Std. Deviation	Std. Error Mean
Lab_ESR	First Nation	252	17.540	24.5409	1.5459
	Caucasian	633	14.107	20.9857	.8341
Lab_CRP	First Nation	252	11.1906	18.47380	1.16374
	Caucasian	633	11.0731	22.56756	.89698
Lab_RF	First Nation	252	205.994	604.1745	38.0594
	Caucasian	633	101.732	276.3627	10.9844

Independent Samples Test										
		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Lab_ESR	Equal variances assumed	3.786	.052	2.089	883	.037	3.4323	1.6427	.2081	6.6564
	Equal variances not assumed			1.954	404.786	.051	3.4323	1.7566	-.0209	6.8855
Lab_CRP	Equal variances assumed	.961	.327	.073	883	.941	.11757	1.60019	-3.02305	3.25819
	Equal variances not assumed			.080	559.410	.936	.11757	1.46931	-2.76846	3.00360
Lab_RF	Equal variances assumed	26.559	.000	3.517	883	.000	104.263	29.6473	46.0753	162.4501
	Equal variances not assumed			2.632	293.747	.009	104.263	39.6128	26.3017	182.2236

Self-reported disease measures

Group Statistics

	Ethnic_Code	N	Mean	Std. Deviation	Std. Error Mean
Pain_VAS	First Nation	252	50.163	30.8665	1.9444
	Caucasian	633	42.087	28.5317	1.1340
HAQ_Score	First Nation	252	.79216	.628542	.039594
	Caucasian	633	.61118	.549657	.021847
Am_Stiff_Rating	First Nation	252	99.603	154.3022	9.7201
	Caucasian	633	77.697	113.0412	4.4930
Fatigue	First Nation	252	48.857	32.3632	2.0387
	Caucasian	633	47.856	32.0104	1.2723

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Pain_VAS	Equal variances assumed	1.163	.281	3.711	883	.000	8.0758	2.1760	3.805	12.3466
	Equal variances not assumed			3.588	430.994	.000	8.0758	2.2509	3.652	12.5000
HAQ_Score	Equal variances assumed	5.373	.021	4.239	883	.000	.180986	.042694	.0972	.264779
	Equal variances not assumed			4.002	411.933	.000	.180986	.045222	.0920	.269880
Am_Stiff_Rating	Equal variances assumed	7.541	.006	2.331	883	.020	21.9065	9.3963	3.465	40.3482
	Equal variances not assumed			2.046	363.133	.042	21.9065	10.7083	.8484	42.9646
Fatigue	Equal variances assumed	.044	.835	.418	883	.676	1.0009	2.3918	-3.693	5.6952
	Equal variances not assumed			.417	457.054	.677	1.0009	2.4031	-.7216	5.7234

Physician Clinical Assessments

Group Statistics

	Ethnic_Code	N	Mean	Std. Deviation	Std. Error Mean
Lansbury	First Nation	252	43.337	44.2251	2.7859
	Caucasian	633	31.564	36.6714	1.4576
MD_Global	First Nation	252	19.635	21.1736	1.3338
	Caucasian	632	16.323	18.5468	.7378
Affected	First Nation	252	9.659	10.4410	.6577
	Caucasian	633	8.329	9.3007	.3697

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Lansbury	Equal variances assumed	20.050	.000	4.056	883	.000	11.7733	2.9025	6.0767	17.4700
	Equal variances not assumed			3.744	395.5	.000	11.7733	3.1442	5.5919	17.9547
MD_Global	Equal variances assumed	12.828	.000	2.300	882	.022	3.3121	1.4402	.4856	6.1387
	Equal variances not assumed			2.173	412.7	.030	3.3121	1.5242	.3159	6.3084
Affected	Equal variances assumed	5.463	.020	1.853	883	.064	1.3301	.7179	-.0789	2.7392
	Equal variances not assumed			1.763	418.1	.079	1.3301	.7545	-.1529	2.8132

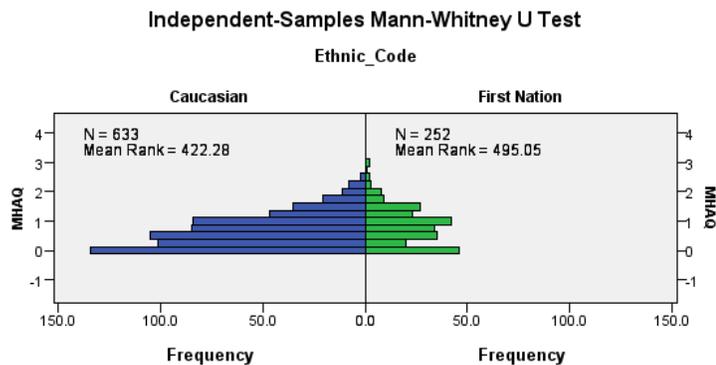
Appendix 12. SPSS Output of Mann-Whitney U Tests of MHAQ, Lansbury Index, Pain, and Affected Joint Count

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The distribution of MHAQ is the same across categories of Ethnic_Code.	Independent-Samples Mann-Whitney U Test	.000	Reject the null hypothesis.
2	The distribution of Lansbury is the same across categories of Ethnic_Code.	Independent-Samples Mann-Whitney U Test	.002	Reject the null hypothesis.
3	The distribution of AJC is the same across categories of Ethnic_Code.	Independent-Samples Mann-Whitney U Test	.184	Retain the null hypothesis.
4	The distribution of Pain_VAS is the same across categories of Ethnic_Code.	Independent-Samples Mann-Whitney U Test	.001	Reject the null hypothesis.

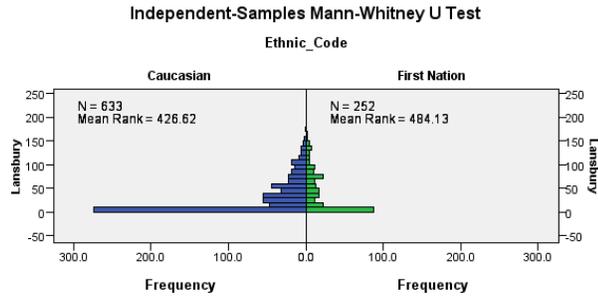
Asymptotic significances are displayed. The significance level is .05.

MHAQ



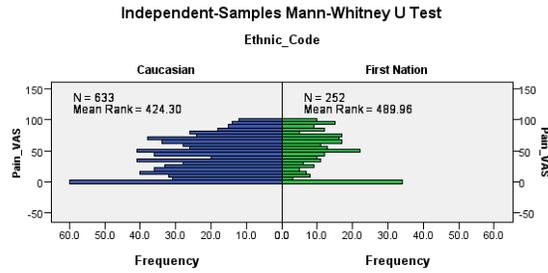
Total N	885
Mann-Whitney U	66,640.500
Wilcoxon W	267,301.500
Test Statistic	66,640.500
Standard Error	3,411.513
Standardized Test Statistic	-3.845
Asymptotic Sig. (2-sided test)	.000

Lansbury Index



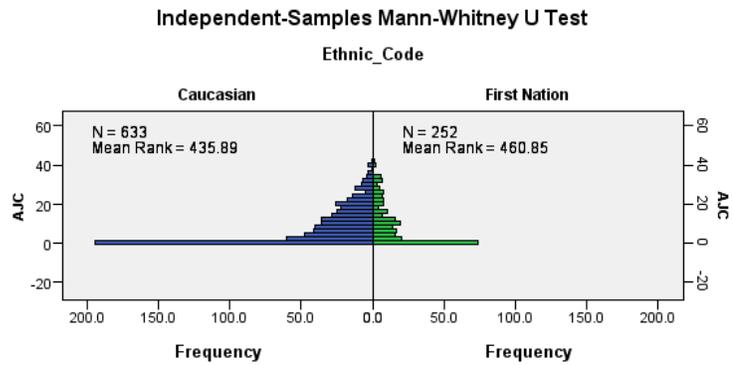
Total N	885
Mann-Whitney U	69,392.500
Wilcoxon W	270,053.500
Test Statistic	69,392.500
Standard Error	3,382.086
Standardized Test Statistic	-3.065
Asymptotic Sig. (2-sided test)	.002

Pain VAS



Total N	885
Mann-Whitney U	67,923.500
Wilcoxon W	268,584.500
Test Statistic	67,923.500
Standard Error	3,430.835
Standardized Test Statistic	-3.449
Asymptotic Sig. (2-sided test)	.001

Affected Joint Count



Total N	885
Mann-Whitney U	75,259.000
Wilcoxon W	275,920.000
Test Statistic	75,259.000
Standard Error	3,382.807
Standardized Test Statistic	-1.330
Asymptotic Sig. (2-sided test)	.184

Appendix 13. SPSS Output of Chi-Squared and Kendall Tau-b tests of “dress yourself”

Crosstab

Count		Ethnic_Code		Total
		First Nation	Caucasian	
HAQ_Dress_Rating	.0	96	276	372
	1.0	118	280	398
	2.0	30	60	90
	3.0	8	17	25
Total		252	633	885

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	2.765 ^a	3	.429
Likelihood Ratio	2.753	3	.431
Linear-by-Linear Association	2.524	1	.112
N of Valid Cases	885		

a. 0 cells (0.0%) have expected count less than 5. The minimum expected count is 7.12.

Symmetric Measures

		Value	Asymp. Std. Error ^a	Approx. T ^b	Approx. Sig.
Ordinal by Ordinal	Kendall's tau-b	-.053	.032	-1.642	.101
N of Valid Cases		885			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Appendix 14. SPSS Output of Partial Correlation between MHAQ and Pain (parametric & nonparametric)

Descriptive Statistics

	Mean	Std. Deviation	N
HAQ_Score	.66271	.578662	885
Pain_VAS	44.38644	29.424684	885
Ethnic_Code	5.14576	1.354645	885

Correlations

Control Variables			HAQ_Score	Pain_VAS
Ethnic_Code	HAQ_Score	Correlation	1.000	.574
		Significance (2-tailed)	.	.000
		Df	0	882
Pain_VAS	Pain_VAS	Correlation	.574	1.000
		Significance (2-tailed)	.000	.
		Df	882	0

Nonparametric Correlations

Correlations

			HAQ_Score	Pain_VAS
Kendall's tau_b	HAQ_Score	Correlation Coefficient	1.000	.465**
		Sig. (2-tailed)	.	.000
		N	885	885
	Pain_VAS	Correlation Coefficient	.465**	1.000
		Sig. (2-tailed)	.000	.
		N	885	885
Spearman's rho	HAQ_Score	Correlation Coefficient	1.000	.615**
		Sig. (2-tailed)	.	.000
		N	885	885
	Pain_VAS	Correlation Coefficient	.615**	1.000
		Sig. (2-tailed)	.000	.
		N	885	885

** . Correlation is significant at the 0.01 level (2-tailed).

Appendix 15. SPSS Output of Multiple Linear Regression of MHAQ

```

REGRESSION
/DESCRIPTIVES MEAN STDDEV CORR SIG N
/MISSING LISTWISE
/STATISTICS COEFF OUTS CI(95) R ANOVA COLLIN TOL CHANGE ZPP
/CRITERIA=PIN(.05) POUT(.10)
/NOORIGIN
/DEPENDENT HAQ_Score
/METHOD=ENTER Pain_VAS
/METHOD=ENTER MD_Global
/METHOD=ENTER School Ageatfirstvisityearsmoonths Duration.3
/PARTIALPLOT ALL
/SCATTERPLOT=(*ZRESID ,*ZPRED)
/RESIDUALS DURBIN HISTOGRAM(ZRESID) NORMPROB(ZRESID)
/SAVE PRED ZPRED ADJPRED SEPRD MAHAL COOK LEVER RESID ZRESID SRESID DRESID
SDRESID DFBETA SDBETA.
    
```

Descriptive Statistics

	Mean	Std. Deviation	N
MHAQ	.66346	.578559	884
Pain_VAS	44.437	29.4034	884
MD_Global	17.267	19.3776	884
years of schooling	10.58	4.676	884
Age at first visit (years, months)	18224.65	6118.205	884
disease duration in years	22.885	35.9380	884

ANOVA^a

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	99.745	1	99.745	449.259	.000 ^b
	Residual	195.822	882	.222		
	Total	295.567	883			
2	Regression	105.061	2	52.531	242.930	.000 ^c
	Residual	190.506	881	.216		
	Total	295.567	883			
3	Regression	109.867	5	21.973	103.892	.000 ^d
	Residual	185.700	878	.212		
	Total	295.567	883			

a. Dependent Variable: MHAQ

b. Predictors: (Constant), Pain_VAS

c. Predictors: (Constant), Pain_VAS, MD_Global

d. Predictors: (Constant), Pain_VAS, MD_Global, years of schooling, disease duration in years, Age at first visit (years, months)

Correlations

		MHAQ	Pain_VAS	MD_Global	years of schooling	Age at first visit (years, months)	disease duration in years
Pearson Correlation	MHAQ	1.000	.581	.270	-.119	.127	.065
	Pain_VAS	.581	1.000	.241	-.046	.068	.048
	MD_Global	.270	.241	1.000	-.052	.037	-.116
	years of schooling	-.119	-.046	-.052	1.000	-.153	.009
	Age at first visit (years, months)	.127	.068	.037	-.153	1.000	-.027
	disease duration in years	.065	.048	-.116	.009	-.027	1.000
Sig. (1-tailed)	MHAQ	.	.000	.000	.000	.000	.027
	Pain_VAS	.000	.	.000	.088	.022	.075
	MD_Global	.000	.000	.	.062	.134	.000
	years of schooling	.000	.088	.062	.	.000	.390
	Age at first visit (years, months)	.000	.022	.134	.000	.	.208
	disease duration in years	.027	.075	.000	.390	.208	.
N	MHAQ	884	884	884	884	884	884
	Pain_VAS	884	884	884	884	884	884
	MD_Global	884	884	884	884	884	884
	years of schooling	884	884	884	884	884	884
	Age at first visit (years,months)	884	884	884	884	884	884
	disease duration in years	884	884	884	884	884	884

Model Summary^d

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics					Durbin-Watson
					R Square Change	F Change	df1	df2	Sig. F Change	
1	.581 ^a	.337	.337	.471191	.337	449.259	1	882	.000	
2	.596 ^b	.355	.354	.465014	.018	24.586	1	881	.000	
3	.610 ^c	.372	.368	.459895	.016	7.574	3	878	.000	1.956

a. Predictors: (Constant), Pain_VAS

b. Predictors: (Constant), Pain_VAS, MD_Global

c. Predictors: (Constant), Pain_VAS, MD_Global, years of schooling, disease duration in years, Age at first visit (years,months)

d. Dependent Variable: MHAQ

Coefficients^a

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.	95.0% Confidence Interval for B		Correlations			Collinearity Statistics	
	B	Std. Error	Beta			Lower Bound	Upper Bound	Zero-order	Partial	Part	Tolerance	VIF
	1 (Constant)	.156	.029				5.413	.000	.099	.212		
Pain_VAS	.011	.001	.581	21.196	.000	.010	.012	.581	.581	.581	1.000	1.000
2 (Constant)	.113	.030		3.829	.000	.055	.171					
Pain_VAS	.011	.001	.548	19.654	.000	.010	.012	.581	.552	.532	.942	1.061
MD_Global	.004	.001	.138	4.958	.000	.002	.006	.270	.165	.134	.942	1.061
3 (Constant)	.071	.070		1.013	.311	-.066	.207					
Pain_VAS	.011	.001	.536	19.329	.000	.009	.012	.581	.546	.517	.932	1.073
MD_Global	.004	.001	.141	5.067	.000	.003	.006	.270	.169	.136	.924	1.082
years of schooling	-.009	.003	-.077	-2.823	.005	-.016	-.003	-.119	-.095	-.076	.974	1.027
Age at first visit (yrs)	7.171E-6	.000	.076	2.795	.005	.000	.000	.127	.094	.075	.972	1.029
disease duration (yrs)	.001	.000	.058	2.139	.033	.000	.002	.065	.072	.057	.980	1.021

a. Dependent Variable: MHAQ

Collinearity Diagnostics^a

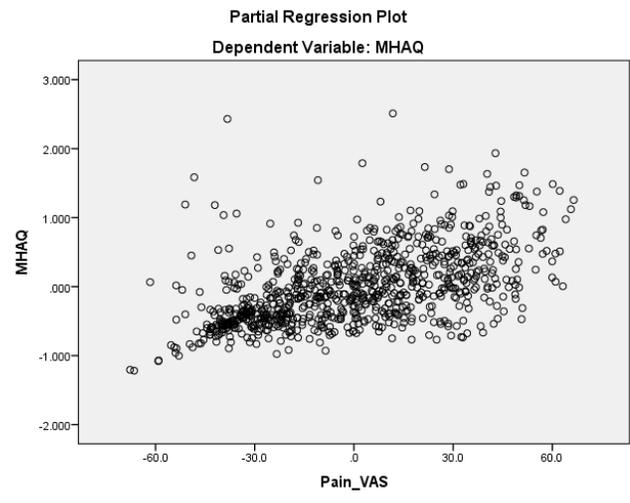
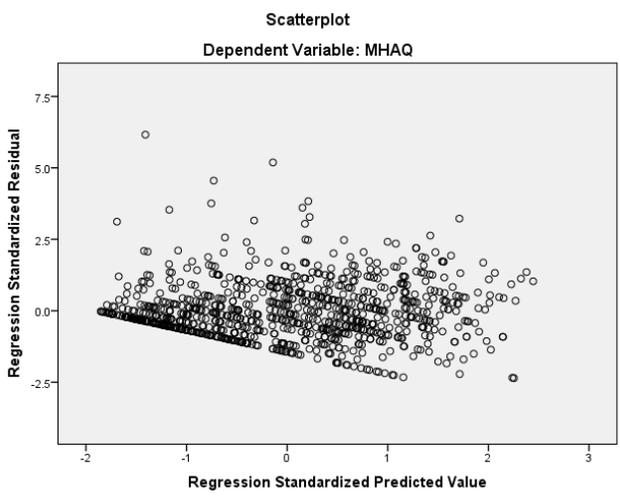
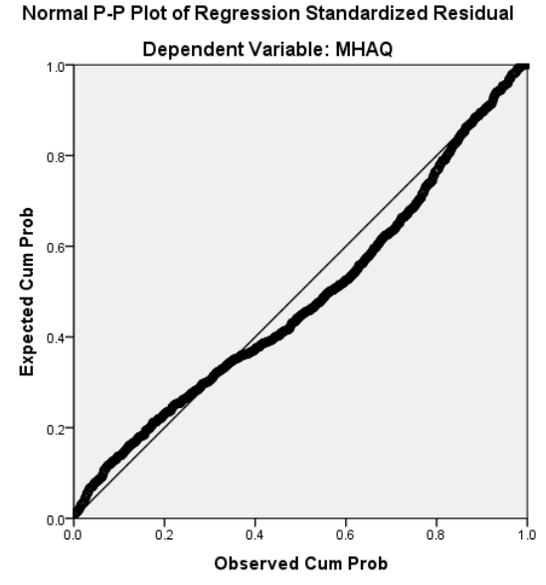
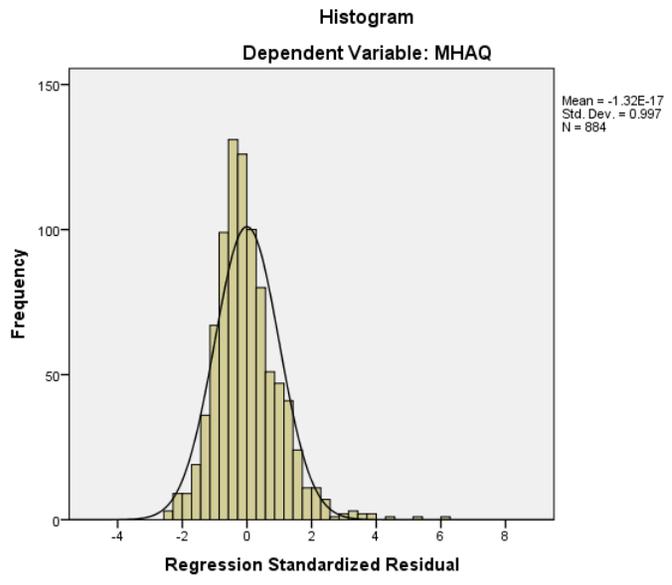
Model	Dimensio n	Eigenvalue	Condition Index	Variance Proportions					
				(Constant)	Pain_VAS	MD_Global	years of schooling	Age at first visit (years,months)	disease duration in years
1	1	1.834	1.000	.08	.08				
	2	.166	3.325	.92	.92				
2	1	2.439	1.000	.04	.04	.06			
	2	.395	2.484	.09	.12	.93			
	3	.166	3.837	.87	.84	.00			
3	1	4.398	1.000	.00	.01	.01	.01	.00	.01
	2	.737	2.443	.00	.00	.16	.00	.00	.71
	3	.434	3.185	.01	.00	.69	.05	.02	.25
	4	.248	4.207	.00	.87	.12	.10	.00	.00
	5	.148	5.453	.01	.08	.00	.48	.33	.00
	6	.034	11.293	.98	.04	.01	.37	.65	.02

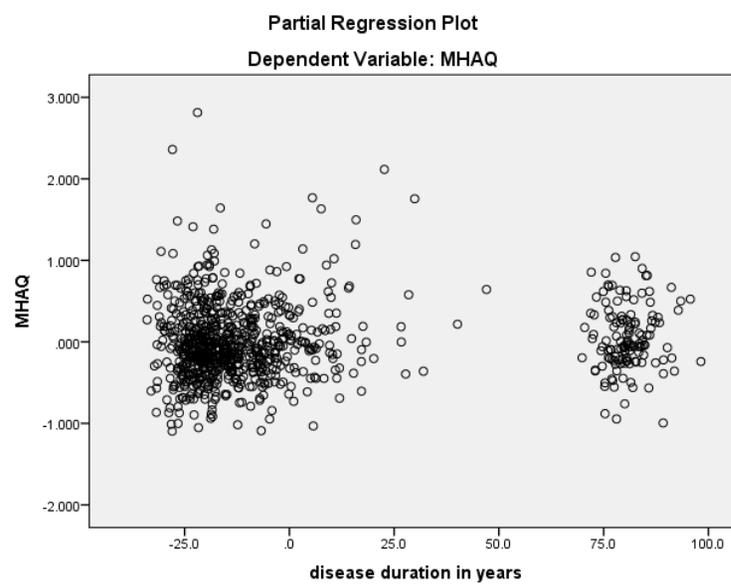
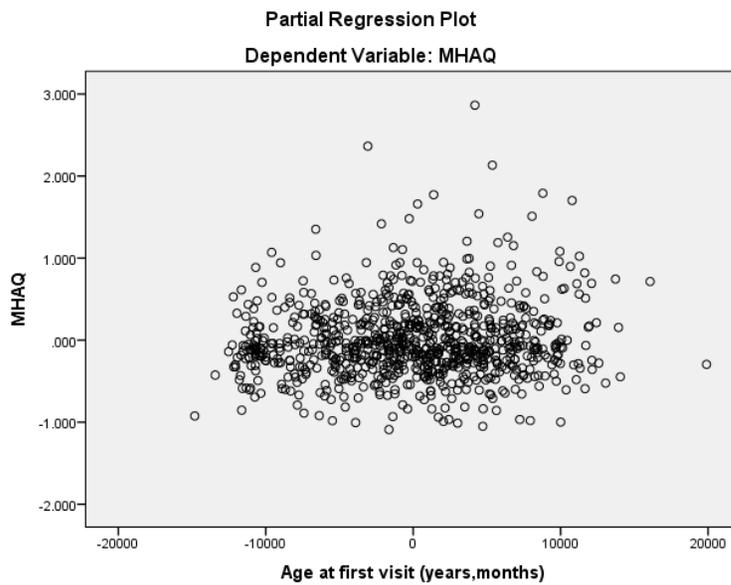
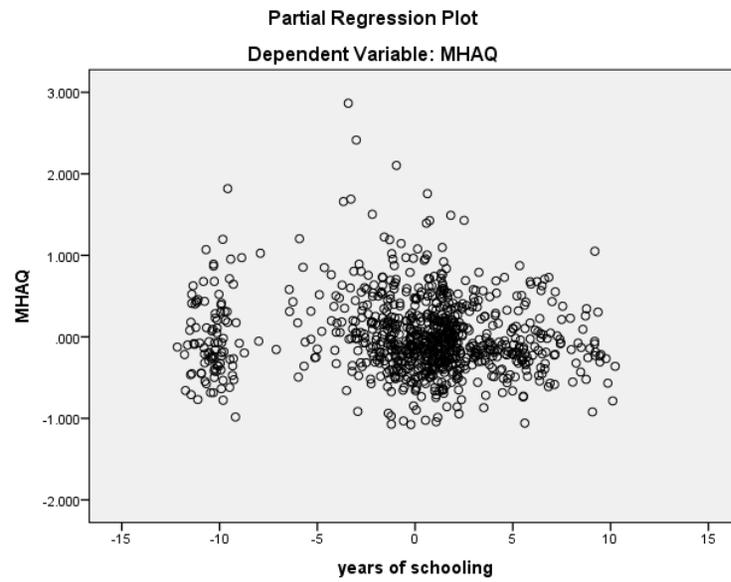
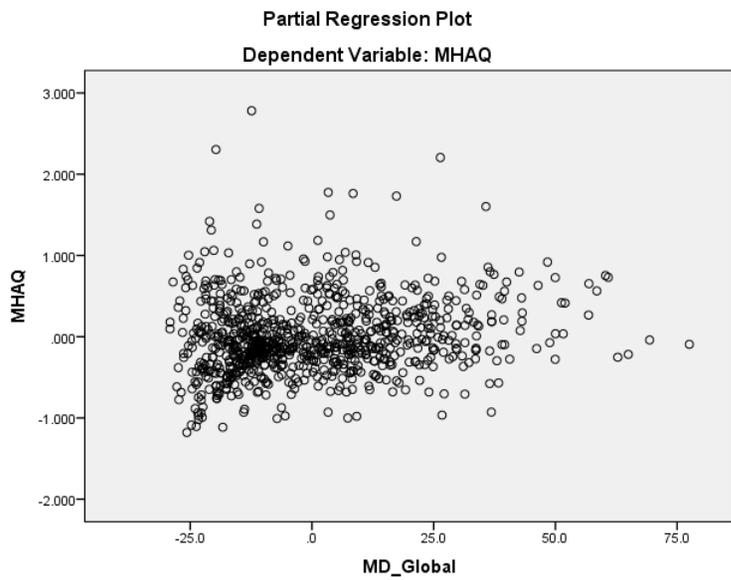
a. Dependent Variable: MHAQ

Residuals Statistics^a

	Minimum	Maximum	Mean	Std. Deviation	N
Predicted Value	.01041	1.52583	.66346	.352740	884
Std. Predicted Value	-1.851	2.445	.000	1.000	884
Standard Error of Predicted Value	.016	.078	.037	.010	884
Adjusted Predicted Value	.01049	1.51717	.66353	.352705	884
Residual	-1.083551	2.833589	.000000	.458591	884
Std. Residual	-2.356	6.161	.000	.997	884
Stud. Residual	-2.368	6.180	.000	1.001	884
Deleted Residual	-1.094813	2.850374	-.000069	.461762	884
Stud. Deleted Residual	-2.375	6.315	.001	1.004	884
Mahal. Distance	.136	24.411	4.994	3.287	884
Cook's Distance	.000	.038	.001	.003	884
Centered Leverage Value	.000	.028	.006	.004	884

a. Dependent Variable: MHAQ





Appendix 16. Convergence Coding Matrix

Case	MHAQ QUESTION							
	1. Dressing self	2. Getting in/out of bed	3. Drinking	4. Walking outside on uneven ground	5. Washing & drying self	6. Picking up object from floor	7. Turning faucets on & off	8. Getting in/out of vehicles
1	PA	A	A	A	A	PA	A	A
2	PA	A	A	A	A	PA	PA	D
3	D	A	A	A	A	A	A	D
4	D	A	A	PA	PA	A	PA	D
5	A	A	A	D	A	A	A	A
6	D	D	D	D	PA	PA	A	PA
7	D	PA	PA	PA	D	A	D	A
8	D	D	PA	A	S	S	S	D
9	S	S	A	A	A	S	D	A
10	D	A	A	A	A	A	A	A
11	D	A	A	PA	PA	PA	A	A
12	D	A	A	D	A	PA	A	PA
13	A	A	A	D	PA	D	S	D
14	D	A	D	A	A	A	D	D
15	A	PA	A	A	A	A	A	A
16	A	PA	A	A	A	A	A	A
17	A	PA	PA	A	A	A	A	A
18	D	A	A	PA	S	A	A	A
19	A	A	PA	A	A	A	A	A
20	A	A	A	A	A	A	A	A
21	D	D	A	D	A	A	A	A
22	A	A	A	A	A	A	A	A
23	PA	A	A	A	S	A	A	PA
24	A	A	A	PA	A	A	PA	A
25	A	A	A	A	A	PA	A	A

A=Agreement; PA=Partial Agreement; S=Silence; D=Dissonance