

NEEDING TO BE NORMAL: UNDERSTANDING THE EXPERIENCES AND
BARRIERS OF YOUNG MEN WITH ANKYLOSING SPONDYLITIS

by

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Dedication

I dedicate this thesis to the seven men who I had the opportunity to meet over the course of this research. You are all strong individuals who have surmounted many obstacles in your lives and I feel privileged to have been able to get to know each of you. I want to thank each of you for opening up your lives to me and sharing your stories. Best of luck to each of you on the path forward.

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Abstract

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Objective: To understand the experiences of young men living with Ankylosing Spondylitis (AS).

Methods: Using an interpretive phenomenological research approach, two semi-structured interviews were conducted with 7 male informants ranging from ages 22 – 37. All of the informants lived in Nova Scotia and had been diagnosed with AS for at least one year. Thematic analysis was used to analyze the data.

Results & Conclusions: Informants displayed a strong affinity to hegemonic masculine behaviours. The overriding theme was *I'm a Man*. The four emerging themes were: *Trying to maintain normalcy*, *Do what I like to do*, *I have to work*, and *I don't really ask for support*. Several barriers to support and health care access were identified that have implications for health promotion, the men themselves, and various AS care providers.

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Chapter 1: Introduction

According to the Arthritis Community Research and Evaluation Unit (ACREU) (2003), arthritis costs Canadians \$4.4 billion each year making it one of the most costly disease in Canada. The highest direct costs associated with diagnosing and treating arthritis were hospital care and drug expenditures at \$458 million and \$263 million respectively; however, 80% of arthritis costs are indirect such as mortality and morbidity costs and, of these, the majority resulted from the impact of long-term disability (ACREU, 2003). Given the magnitude of the financial resources necessary for managing arthritis, any efforts that can reduce these costs and improve the management of arthritis can have a substantial impact on overall health care in Canada, and the quality of life of those who live with arthritis. It is particularly appropriate to address arthritis concerns for Nova Scotians given that ACREU (2003) reports that Nova Scotia has the highest rate of arthritis in Canada at 23.3% that is 7.3% higher than the Canadian average.

Arthritis is a group of more than 100 diseases that cause deterioration of the joints and related structures in men, women and children (ACREU, 2003; Public Health Agency of Canada, 2009). Arthritis affects not only the joints but can cause problems in the ligaments, tendons and internal organs (ACREU, 2003). While all arthritis is characterized by pain and fatigue, which can be caused by inflammation in one or more areas of the body (Public Health Agency of Canada, 2009), due to some distinctive differences, the various conditions are generally divided into two broad categories: degenerative and inflammatory arthritis. The most common degenerative form of arthritis, with a prevalence rate of 10% in the Canadian population, is Osteoarthritis. In Osteoarthritis the cartilage in the joints deteriorates as a result of injury generally

associated with wear and tear over a number of years (ACREU, 2003; Public Health Agency of Canada, 2009). Conversely, Rheumatoid Arthritis, the most common inflammatory arthritis with a prevalence of 1%, results when the body's immune system attacks the joints and internal organs (ACREU, 2003).

Of the inflammatory arthritis conditions, two times as many women as men are affected; however, one inflammatory condition, Ankylosing Spondylitis, occurs three times more frequently in men than women particularly affecting young men in the 18-40 year age group (ACREU, 2003; Chorus, Miedema, Boonen, & van der Linden, 2003). While not a large number compared to the overall incidence of other types of inflammatory arthritis, Ankylosing Spondylitis is an important inflammatory condition affecting approximately 4500 people living in Nova Scotia of whom 3000 are men (Elyan & Khan, 2006; Statistics Canada, 2009). These men enter their young adulthood, often considered the prime of the life course period, faced with the same challenges as others but also with the additional challenges associated with living with a chronic illness (Davis, Wong, Badley, & Gignac, 2009).

Ankylosing Spondylitis

Ankylosing Spondylitis (AS) is a chronic systemic inflammatory arthritis, considered to be a Spondyloarthropathy (SpA) (a group of arthritides that affects the axial skeleton - the spine and sacroiliac joints) leading to fusion of the spine (Cakar et al., 2007; Ozgul et al., 2006; Yim, et al., 2003). Hip and shoulder joints are often affected, but it is rare to have peripheral joint involvement such as the feet and hands (Cakar et al., 2007; Ozgul et al., 2006). Other than AS, the most notable of the SpAs is Psoriatic Arthritis that causes inflammation in and around the spine as well as smaller joints in the

hands and feet at tendon insertion points (Abdelmoula et al., 2008; Hamilton, 2008).

Crohn's Disease and Ulcerative Colitis, both forms of inflammatory bowel disease, can be associated in people with AS (Beslek et al., 2008).

AS is characterized by acute inflammatory episodes (flare-ups) and periods of remission (ACREU, 2003; Sierakowska et al., 2006). These remissions and exacerbations are unpredictable sometimes presenting for a brief period (days) while other times for an extended period of time (months) (Klippel, Stone, Crofford, & White, 2008). AS exacerbations often lead to a variety of physical ailments. Pain, stiffness, fatigue and physical disability can affect potential employment, current employment, and leisure activities that require moderate to intense physical exertion (Chorus et al., 2003; Sieper, 2009; Van Tubergen et al., 2002). Similarly, pain and fatigue can affect intimate relationships. For example, in their study, Ward, Reveille, Learch, Davis Jr., and Weisman (2008) reported that people living with AS were more likely to have never been married or to be divorced than their healthy counterparts while Pirildar et al. (2004) reported that men with AS showed lower levels of erectile function and overall sexual satisfaction than the general population. As well as these physical effects, AS poses daily emotional and psychosocial challenges.

Some of the emotional challenges confronting those with AS include loss of independence, worry about money, body image, and self-confidence (Gignac, Cott & Badley, 2000; Ozgul et al., 2006). Growing dependence on others as a result of disability, pain levels, or fatigue has been reported as making people feel needy, helpless, incompetent and incapable (Gignac et al., 2000). This waning of independence is especially difficult when people who have been working are forced to leave the

workplace (Ozgul et al., 2006) or those anticipating employment have their opportunities reduced. Changes in employment status and opportunities can, in turn, impact relationships with family and friends, expectations for the future, and self-confidence (Ozgul et al., 2006). These expectations are particularly important given that AS is a disease that is most often diagnosed in the early adult stage of life (Chorus et al., 2003; Sieper, 2009).

Many of those newly diagnosed with AS are adjusting to the knowledge that they have an incurable disease with potentially significant physical damage while making the transition into adulthood; a transition that involves decisions about career, relationships, and education (Gerhardt et al., 2008; Scal et al., 2009). Despite these challenges, there is surprising little research on AS and these concerns. Nevertheless, there is a growing body of research about transitioning into adulthood with other chronic illnesses including other types of arthritis.

Scal et al. (2009) in their study of pediatric rheumatology patients who are transitioning to adult rheumatology clinics discuss the need for counselling young people through this time of their life even though young people may not be receptive to it. Gerhardt et al. (2008), in their examination of children and youth between the ages of 8-14 years with juvenile idiopathic arthritis note that people between the ages of 18 and 25 are faced with the majority of the decisions that will decide their long-term income levels and socioeconomic status. Recognizing the importance of these critical life decisions, McDonagh (2008), a transition pioneer in the United Kingdom (UK), advocates that the medical and support team for young people with chronic illnesses should be addressing emotional, psychosocial and educational issues as well as medical issues. As part of its

solution, the UK provides transition clinics that continue relationships with former paediatric patients until the age of 23 (McDonagh, 2008). Evaluation results indicate there is benefit to continuing the counselling process into early adulthood.

Rationale and Research Question

Arthritis research has explored various psychosocial and medical impacts through research designs that have included both women and men or women alone. This has been an understandable focus given that women are nearly two times more likely than men to be affected by arthritis (ACREU, 2003). However, recent research on managing chronic diseases has noted that disease outcomes are affected by important biological differences between males and females in their responses to various treatment regimens as well as their differing social and emotional responses (Yim et al., 2003). Despite a growing body of medical information about the physical effects of inflammatory arthritis, including AS, its treatment, and an expanding body of evidence about women's experience with various types of arthritis, there is little evidence about the social and emotional impact of men's inflammatory arthritis experiences and none about the experiences of men with AS, or the impact on life decisions they undertake (Pirildar et al., 2004). Those decisions and challenges occur around employment, physical activities, intimate relationships, parenthood, and other aspects of their day-to-day lives (Cakar et al., 2007; Chorus et al., 2003; Sieper, 2009). As a way to fill some of these gaps, this project sought to explore the lives of young men with AS. The specific research question was:

What is the day-to-day experience of young men with Ankylosing Spondylitis?

There were two subsidiary questions:

How does Ankylosing Spondylitis impact men's work and personal lives?

What are the barriers, if any, to accessing services and supports for men with a diagnosis of Ankylosing Spondylitis?

Research Significance

Understanding the life experiences of young men with Ankylosing Spondylitis is not easily explored through conventional quantitative approaches because these approaches generally rely on categorical responses. If the category identified by the researcher and the existing literature do not fit with the experience of the research participant, then rich, important data are lost (Patton, 2002). While the extant literature provides valuable medical information, as well as some social and emotional context for AS, it does not allow for in-depth examination of the participants' social and emotional experiences and their various social roles (Davis et al., 2009). The majority of the current research for people living with AS is based on a medical model which is generally designed to improve diagnostic and treatment approaches, rather than to examine the broader influences on health such as the psychological, social, and environmental factors that impact a person's life (Davis et al., 2009).

Davis et al. (2009) note that the "2005 Summit on the Standards for Arthritis Prevention and Care . . . identified participation in family and societal roles as an important and meaningful outcome for people with arthritis" (p. 46). Participation is defined as "a measure of involvement in social roles (e.g. employment, education, leisure activities, and interpersonal relationships) that takes into account the meaning of the activity for the individual, as well as the individual's satisfaction with the time spent on a

role and their [*sic*] performance in that role” (Davis et al., 2009, pp. 50-51). The relationship between social role participation and AS has not yet been explored, yet there is precedent in other chronic illnesses that increased participation leads to an improved overall belief in a person’s sense of well-being (Davis et al., 2009). Of all social role participation for people with AS, employment has been examined most often (Davis et al., 2009; Gignac, Cao, Lacaille, Anis, & Badley, 2008; Ozgul et al., 2006); however, familial roles and impact on educational aspirations have been investigated only tangentially. Based on the existing literature and the gaps identified by Davis et al. (2009), this proposed research will contribute to closing some of those gaps.

This proposed research may also assist those currently treating men with AS since emotional health, in particular poor emotional health, is known to impact disease trajectory (Martindale et al., 2006). The research may also allow men living with AS to find themselves represented in the literature. This representation has been shown to be important to those living with other chronic conditions (Hutchinson, Wilson, & Wilson, 1994; Sandelowski, 1993).

Definition of Terms

To assist the reader, terms used throughout the thesis have been defined below.

Ankylosing Spondylitis. A chronic inflammatory joint disease that chiefly affects the sacroiliac joints and the spine (Pham, 2008).

Arthritis. Rheumatic diseases and conditions that affect the joints and tissues that surround the joint and other connective tissue, often characterized by inflammation (ACREU, 2003).

Chapter 2: Literature Review

This chapter will review the literature on AS as it relates to significant life experiences during young adulthood. The chapter is divided into three sections, the first is the impact of AS primarily on the physical health of those affected. The second part of the chapter discusses psychosocial issues as they relate to the personal and working life of those diagnosed with AS. Finally, the chapter discusses the challenges to collecting incidence and prevalence information about the population of those living with AS.

Physical Health of Those With AS

AS has an impact on the physical health of those affected. Part of that impact is related to the challenges associated with its diagnosis, management, and treatment. The following sections will highlight the importance of an accurate diagnosis and the variety of management options including medications, physical activity, and complementary therapies.

AS diagnosis. Most new cases of AS occur in young men in their 20s, although it is not uncommon for the disease to present in the late teen years as well (Shaikh, 2007). Most people living with AS will seek initial aid from a primary health care physician such as a chiropractor or a family physician because they are experiencing low back pain. Their diagnosis is usually determined to be inflammatory back pain (Shaikh, 2007) as opposed to mechanical low back pain. Inflammatory back pain, where the inflammation is not necessarily the cause of the arthritis, found in the axial skeleton (head, neck, spine, and ribcage), becomes evident during coughing or sneezing (Klippel et al., 2008; Shaikh, 2007). More commonly, the hips and shoulders will also be inflamed, causing localized tenderness, aiding in the diagnosis (Klippel et al., 2008; Shaikh, 2007). Enthesitis

(inflammation at muscle insertion points) is also a common manifestation in people living with AS and is, therefore, helpful in reaching a diagnosis. Shaikh (2007) reports that enthesitis is common in the spine as well as the shoulders, hips, plantar fascia, and Achilles tendon. Similarly, iritis (inflammation of the iris) is common in 20% - 40% of the population with AS, resulting in eye pain, redness, blurriness and photophobia (Shaikh, 2007). Psoriasis occurs in approximately 9% of the AS population in Canada and inflammatory bowel disease also affects 6% of people with AS also (Shaikh, 2007). As AS is a systemic disease affecting the internal organs as well as the musculoskeletal system, people living with the disease sometimes present with cardiovascular challenges such as aortic insufficiency and myocardial infarction (Klippel et al., 2008; Shaikh, 2007). Furthermore, people living with AS are at an increased risk for osteoporosis, vertebral compression fractures, spinal rigidity and kyphosis (Shaikh, 2007).

As with other chronic diseases, AS ranges from mild cases where there are periods of both remission and active disease (exacerbations) to continuously progressive cases where disease activity is sustained for extended periods (Sierakowska et al., 2006). While assessing the severity of AS is possible through measurement tools such as the Bath Ankylosing Spondylitis Disease Activity Index (BASDAI) and Bath Ankylosing Spondylitis Functional Index (BASFI), predicting the level of severity of AS is not easily accomplished. Hamersma et al. (2001) investigated possible genetic links to predicting severity. In their study of 173 families living with at least one case of AS, they found the strongest similarity of AS severity in twins, but also noted a strong correlation in the remainder of the sample with respect to the relationship between disease activity and functional level.

In order to identify AS in its early stages and begin early treatment, people who experience symptoms of AS, such as swelling, redness and back pain persisting more than three months, should seek medical attention (SAA, 2010b). Unfortunately, the general signs and symptoms of the condition are often confused with a variety of other illnesses (Symmons, 2002). Historically, there has been approximately a 7-10 year gap between the date of onset of AS and its diagnosis (Shaikh, 2007). This is a result of three key factors: the gender of the majority of the population, the health care service that is sought, and the insensitivity of conventional imaging.

Shaikh (2007) reports that men, the population twice as likely to be affected by AS as women, are unlikely to seek any type of care and when they do, it is most often from a chiropractor or family physician. These latter health care personnel may not be the best equipped to diagnose AS. When a primary care physician, such as a family physician, suspects AS or one of the other forms of inflammatory arthritis, he/she may assume treatment for the patient's arthritis or refer the patient to a rheumatologist. All referrals to rheumatologists are then triaged. There are four categories into which patients are categorized: emergent, urgent, semi-urgent, and non-urgent (Dalhousie University, 2010). Each of the categories has its own targeted timeline for the patient to be seen by a rheumatologist. Emergent cases, such as septic arthritis or vasculitis, are meant to be seen within 24 hours of referral (Dalhousie University, 2010). Urgent cases, comprised of acute monoarthritis and polyarthritis with functional impairment, are targeted to be seen within four weeks of referral (Dalhousie University, 2010). Semi-urgent and non-urgent referrals are planned to be seen within 12 weeks and 24 weeks, respectively (Dalhousie University, 2010).

Currently, rheumatologists are screening patients based on the New York criteria for diagnosing AS which requires advanced radiographic changes to be evident. This can be problematic because a population with recent onset is unlikely to show significant damage on an x-ray (Shaikh, 2007). This problem has been partially offset by recent medical advances include the use of Magnetic Resonance Imaging (MRI) to aid in a diagnosis of AS. An MRI can detect inflammation in the common sites of AS long before any damage occurs in the joints and surrounding areas (Shaikh, 2007).

There is a significant amount of literature that discusses AS and its impact on physical function. Landewe et al. (2009), in their review of the Outcome in Ankylosing Spondylitis International Study (OASIS) database, included 217 people living with AS in their study of physical function and its relationship to disease activity and radiographic damage. Landewe et al. proposed that physical function can be categorized into those matters that are reversible and those that are irreversible. The reversible component is due to signs and symptoms that are patient reported through such means as a Health Assessment Questionnaire (HAQ) and the irreversible constituted radiographic images of existing damage. Landewe et al. concluded that physical function is dependent on both disease activity and radiographic damage. Physical function is assessed by tools such as the BASFI and the Dougados Functional Index. The BASFI, in particular, is considered a reliable and valid tool that is used in many research studies (Ariza-Ariza et al., 2003).

In a Belgian epidemiologic study conducted between 2004-2005, Boonen et al. (2009) reviewed questionnaires from 89 rheumatologists. In their study of 619 patients with AS (68% male) aged 32-56, Boonen et al. (2009) report that radiographic spinal changes are more common in men with AS who are younger at disease onset. Boonen et

al. (2009) also report that the BASFI was raised in men who were older and had hip involvement, yet not in those with increased disease duration. Physical function is an important component in the diagnosis and management of AS.

Van Echteld et al. (2006) conducted their research into physical functioning by using the International Classification of Functioning, Disability and Health with 111 people living with AS. They found that 74% of the 111 patients with AS showed limited functionality in terms of their recreation levels, including their ability to walk more than 1 km, or to swim or cycle. As well, as a result of this physical changes certain types of physical work are not recommended for people living with AS because it puts unnecessary pressure on the spine and sacroiliac joints and may result in spinal fracture (de Peretti, Sane, Dran, Razafindratsiva, & Argenson, 2004). For most of those diagnosed by either their family physicians or by their rheumatologist, AS is managed primarily through medication and exercise (Sieper, 2009).

AS management - medication. Non-steroidal anti-inflammatory drugs (NSAIDs) are the first medicinal option for those with AS because they reduce the inflammation in the spine which causes its deterioration and potential fusion (Klippel et al., 2008). If NSAIDs are not effective enough on their own, sulfasalazine, a disease modifying anti-rheumatic drug (DMARD), is used as a final resort before beginning treatment with anti-TNF blockers such as etanercept (Enbrel®), infliximab (Remicade®) and adalimumab (Humira®) (Sieper, 2009). These anti-TNF medications are biologic agents that interrupt the inflammatory process and may slow down the progression of the disease. They have been shown to be highly effective in managing Rheumatoid Arthritis, Psoriatic Arthritis and AS (Sieper, 2009).

McLeod et al. (2007) conducted a meta-analysis of nine different randomized control trials including two of adalimumab, five of etanercept and two of infliximab. McLeod et al. (2007) examined BASDAI and BASFI scores as well as the Assessment in Ankylosing Spondylitis (ASAS) at 20%, 50 % and 70% improvement and found all three agents to be more effective than a placebo. However, they also report that there was no significant difference in outcomes among the three drugs for the effective management of AS (McLeod et al., 2007).

One of the concerns in treatment of AS has been the cost of the medications. McLeod et al. (2007), based in the United Kingdom, considered the costs of chemotherapeutics in their meta analysis examining the cost-effectiveness and average costs per patient in pounds / Quality Adjusted Life Year (QALY). They found that there was a difference between medications with etanercept and adalimumab averaging just below 30,000 pounds (\$60,000 CDN) and Infliximab which averaged between 40,000 and 50,000 pounds / QALY (\$80,000-100,000 CDN). These data demonstrate that the therapies for the most severe cases of AS can be expensive. In addition to having a high cost, anti-TNF therapies, as well as other disease modifying medications, are associated with an increased risk of side effects.

Some of the potential side effects of anti-TNF drugs may include an increased susceptibility to infection including a possible reactivation of tuberculosis and malignancy such as lymphoma (Sieper, 2009). The Canadian Pharmacists Association (CPA) (2008) noted in its compendium of pharmaceuticals, which cites numerous randomized control trials for each medication, that these anti-TNF agents result in a variety of potential side effects. In randomized control trials with 393 AS patients who

used adalimumab, delivered by subcutaneous injection, 13 potential side effects were reported including minor issues such as injection site irritation and pain to more serious concerns such as respiratory infections and nasopharyngitis (CPA, 2007). Patients who used Infliximab, an intravenous infusion, reported 30 different side effects ranging from pain and fatigue to pneumonia and gastroenteritis (CPA, 2007). Sieper (2009) notes in his review of the current AS literature that there have been reported cases of patients with tuberculosis and lymphoma, but they are rare. The CPA (2009) reports that people using the medication etanercept, a subcutaneous injection, claimed 44 potential side effects ranging from dizziness and a rash to an increase in weight and vertigo.

While McLeod et al. (2007) report that there was no significant difference in the effectiveness of the three anti-TNF therapies that were studied, there are potential compliance issues relating to the differing methods of administering the medication. Although not a population with AS, those with Crohn's Disease use some of the same medications. Kane, Chao, and Mulani (2009) in their study of 571 patients with Crohn's Disease, found there was a non-compliance rate of 34.3% in the first year of therapy. Kane et al. (2009) further report that the non-compliant patients were more likely to be hospitalized which in turn led to higher health care costs on average. Borrás-Blasco, Gracia-Perez, Rosique-Robles, Castera, and Abad (2010) indicate in their study of 55 patients using adalimumab that following an education session on how to use the new autoinjection pen, compliance rates were 100%. The Borrás-Blasco et al. (2010) study also showed that the participants thought the new method was easier (86%) and that they preferred it over the previous subcutaneous syringe (96%). These results indicate that the method of delivery is important to patients.

In addition to pharmaceutical interventions, physical exercise/activity is the other cornerstone in the management of AS. Physical activity aids in maintaining mobility, pain, stiffness, function and overall quality of life (Dagfinrud, Kvien, & Hagen, 2008; Elyan & Khan, 2008).

AS management - physical activity. As Ariza-Ariza, Fernandez-Cruz and Navarro-Sarabia (2003) note, “physical function is among the recommended core set of endpoints in AS” (p. 483). These endpoints are outcome measures that determine disease severity and progression and assist in decision making for a medical team. Landewe, Dougados, Mielants, van der Tempel, and van der Heijde (2009) observe that one of the major goals of treatment is to improve physical function and to maintain an acceptable state” (p. 863). Accordingly, AS is managed primarily by maintaining a healthy lifestyle including physical fitness although, as indicated above, this can be challenging when the disease limits mobility and, therefore, the ability to exercise (Elyan & Khan, 2008; Sieper, 2009).

While it is well documented that physical activity is an important part of the treatment regimen for everyone diagnosed with AS, there remains a lack of evidence on which type of physical activity is most effective (Dagfinrud et al., 2008; Elyan & Khan, 2008; Karapolat et al., 2009). Karapolat et al. (2009) randomized 45 patients into three different groups to determine which of three methods of physical activity was most effective in the management of AS: swimming, walking, or conventional exercise. They found that all three treatments had benefits for both quality of life and pulmonary function; however, swimming and walking both showed additional improvement on patient’s functional scores over conventional exercise (Karapolat et al., 2009). Karapolat

et al. (2009) also examined quality of life of AS patients who were participating in physical activity and found that all three groups reported increases in happiness, with the highest scores residing in the swimming group. These findings are consistent with Altan, Bingol, Aslan, and Yurtkuran (2006) who found in their study of 60 patients with AS that there were significant benefits to balneotherapy exercise (a form of spa exercise) in conjunction with conventional exercise over conventional exercise alone. However, Altan et al. (2006) did not record the same consistency in reported levels of quality of life. Improvements were shown with respect to pain, physical activity, sleep, tiredness, and emotional reaction throughout the study, however, the effect of the intervention decreased between the measurements at 3 weeks as compared to at 24 weeks (Altan et al., 2006).

In related research, Elyan and Khan (2008) found that in-patient spa-exercise therapy coupled with group physiotherapy was the most beneficial program for people living with AS, yet most types of physical activity can be of benefit. The most common recommendation for physical activity remains “home-based, unsupervised exercises . . . [where] patients should try to maintain proper posture and avoid stooping or bending if possible” (Harper & Reveille, 2009, p. 32). Despite this evidence that physical therapy and activities are beneficial, Harper and Reveille (2009) caution that there are certain leisure and recreation activities that should be avoided as they can harm the spine. As a result of issues of treatment delivery, side effects, and the moderate success of physical activity, some of those living with AS turn to complementary therapies to supplement the more conventional medical approach (Spondylitis Association of America [SAA], 2010a).

AS management - complementary therapies. Complementary therapies are defined by the National Centre for Complementary and Alternative Medicine (NCCAM) “as a group of diverse medical and health care systems, practices, and products that are not generally considered part of conventional medicine” (2010b, p. 1). The SAA (2010a), a patient-centred not-for-profit organization based in the US, reports the reasons for this shift toward complementary therapies as varied.

Many people want relief for pain and suffering that traditional medications have not provided; they hope to avoid potentially serious side effects associated with such medications; and certain conventional medical and surgical treatments cost more than many of us can afford. (SAA, 2010a, p. 1)

While the concern about costs of surgical treatment may be uniquely American, the relief of pain and suffering is a universal concern of those with chronic illness, leading others to using complementary therapies (SAA, 2010a). The SAA (2010a) recommend six complementary therapies that they say could be used in people with AS: Acupuncture, Massage, TENS (Transcutaneous Electronic Nerve Stimulation), Chiropractic, Oriental Medicine, and Yoga. There is limited research cited by the SAA; however, there are Canadian and American resources that indicate the overall safety of most complementary medicines. Despite this recommendation, there is concern, voiced by American rheumatologist, Dr. Khan and others, that there is increased risk of spinal fracture with the use of chiropractic treatment for people living with AS (NCCAM, 2010a; SAA, 2010a).

NCCAM (2010a) suggests that acupuncture is a safe way of managing pain when the proper techniques are applied. Similarly, massage therapy and yoga are considered to

be low risk therapies for those with AS when applied by trained professionals and under the direction of a physician (NCCAM, 2010a). Yoga is a very common complementary therapy, used by approximately 6% of the American population. Despite these claims by the NCCAM, the safety and effectiveness of complementary therapies are still not well researched; additional research is necessary. Whether through conventional approaches to treatment or complementary therapies, the goal of the person with AS and his/her health care team is to diminish the progression of the disease, and reduce negative psychosocial impact to improve the person's quality of life (QOL) (Ariza-Ariza et al., 2003).

Psychosocial and Behavioural Impacts on AS

AS is a disease that can cause significant deformity, pain, and fatigue (Chorus et al., 2003; Sieper, 2009; Van Tubergen et al., 2002). Additionally, people living with AS face daily emotional and psychosocial challenges (Gignac, Cott & Badley, 2000; Ozgul et al., 2006) such as growing dependence on caregivers, stress about money, body image and self-confidence (Gignac et al., 2000; Ozgul et al., 2006). People living with AS are at risk of losing their independence because of disability, pain levels, or fatigue; affecting their quality of life (ACREU, 2003; Chorus et al., 2003).

Quality of life for those with AS. Quality of life is an important consideration for all rheumatic diseases. The most commonly tool used to measure QOL is the Short Form 36 (SF-36) survey (Ariza-Ariza et al., 2003). Ariza-Ariza et al. report in their study of 92 Spanish patients with AS, of whom 75% were male, that their Health Related Quality of Life (HRQOL) was “impaired in a significant way” (2003, p. 485). They also indicate that physical capacity is more impaired than mental and social elements although these were also important (Ariza-Ariza et al., 2003). Davis et al. (2009) argue that as well as

physical limitations, limitations in people's social role participation in necessary activities are also detrimental. Social participation may particularly affect how men seek help for health problems.

Help-seeking behaviour: AS and masculinity. Men's health behaviour is influenced by many factors such as socioeconomic status, education, and masculinity (Courtenay, 2000; Gibbs, 2005). Masculinity is defined by Galdas et al. (2007) as "a set of socially constructed relationships, which are produced and reproduced through men's actions and interactions" (p. 223). As defined by Galdas et al. (2007), these socially constructed relationships vary depending on the culture within which they are fostered. For example, in western cultures Addis and Mahalik (2003) note that "men are less likely than women to seek help for problems as diverse as depression, substance abuse, physical disabilities, and stressful life events" (p. 5).

With regard to health behaviour, masculinity is a gendered role filled with behavioural expectations for the individual while he seeks social validation (Gershick, 2000). These roles are socialized into men at a very young age and continue to strengthen and solidify into adulthood (Courtenay, 2000; Gershick, 2000). This behaviour demands that men ignore pain and discomfort and be reluctant to seek help from health care providers (Addis & Mahalik, 2003). Galdas et al. (2007) report in their research on white North American and South Asian men's decisions to seek medical help when faced with cardiac chest pain, that differences are apparently a result of cultural influences.

[white, North American men] men who adhere to hegemonic versions of masculinity are reluctant to discuss health problems with others, only contemplate seeking help following pain, endurance, stoicism and visible injury, and need a

means of legitimizing their visit to a doctor to keep their male identity intact.

Thus, the denial of weakness and rejection of help, such as when a man brags ‘I haven’t been to a doctor in years’, has been found to be simultaneously a health practice and a key practice of masculinity in Western culture. (pp. 223-224)

This masculine ideal is thought to be rooted in masculine role socialization (Galdas et al., 2007). Galdas et al. note the response of an Indian or Pakistani man.

No Indian or Pakistani man considered seeking help for their [*sic*] chest pain to be ‘unmanly’ or a sign of weakness. When questioned about what they did consider to be valued male attributes, several men placed great emphasis on wisdom, education and responsibility for the family and their own health. (p. 226)

In other research on the role of masculinity in the context of help-seeking, Addis and Mahalik (2003), posit that men learn their attitudes and behaviours from their cultural influences. Addis and Mahalik (2003) provide examples of several male gendered norms that are valued: self-reliance, physical toughness, and emotional control in North American societies. These findings are consistent with those of Galdas et al. (2007).

In Western societies, men are more likely to be at risk of poor health behaviours than women (Statistics Canada, 2009). For example, Statistics Canada (2009) reports that men are more likely to smoke than their female counterparts. Similarly, men are less likely to have a regular medical doctor and more likely to have high blood pressure (Statistics Canada, 2009). These, along with a host of other risk factors put men at significant increased risk for disability and premature death (Courtenay, 2000; Statistics Canada, 2009). An increased risk for disability is typically associated with increased levels of pain. Men’s reaction to pain is an important component of psychosocial impact

of treatment for men with AS.

Arthritis and pain treatment. Pain is defined as “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, 2010, p. 1). Pain is commonly reported as a symptom in AS (Cakar et al., 2007; Chorus et al., 2003; Ozgul et al., 2006). Pain is both physiological and emotional which results in variations in the way people experience pain (Strong, Unruh, Wright, & Baxter, 2007). These variations in the expression of pain are evident when gender comparisons are made (Strong et al., 2007). Affleck et al. (1999) compared the pain experiences of people living with osteoarthritis and rheumatoid arthritis, finding that men report a lower prevalence and severity of pain than their female counterparts. This confirmed the earlier research by Unruh (1996) who reported that women were more likely to report more severe pain, more frequent pain, and longer lasting pain than men. Hoffmann and Tarzian (2001) also report that women complain about their pain more often than men, and as a result are less likely to be taken seriously.

Affleck et al. (1999) suggest that there are several potential reasons for the gender differences. Some researchers propose that men and women are subjected to different social learning experiences with regard to expressing pain (Affleck et al., 1999). Others indicate that there is a potential difference at a hormonal level. Still others believe that women have lower thresholds at a physiological level than do men (Affleck et al., 1999). Affleck et al. state that despite any potential differences in the cause of reported pain levels, the end result is consistent: men avoid help-seeking behaviours related to their pain. Given that pain is a significant symptom of AS, these responses, either

physiologically based, or the result of gender roles, have important implications for treatment of AS.

Filligim, King, Ribiero-Dasilva, Rahim-Williams, and Riley (2009) discuss gender differences related to various therapeutic techniques that are used to treat pain. In their critical review of the pain literature from the past 10-15 years, Filligim et al. (2009) found that the treatment techniques that produced the most successful results were those most consistent with masculinity theories; men were able to reduce their pain levels most consistently through traditional physical therapy. This is consistent with Addis and Mahalik's (2003) findings that men are socialized to become self-reliant and physically tough. Traditional physical therapy is an example of a treatment that meets masculine social expectations as it can be seen as a measurement tool for men to compare their results with a previous score or measurement. These therapies are usually offered outside a group setting where men are self-reliant (Addis & Mahalik, 2003). Acknowledging these social roles, Filligim et al. (2009) reported that men showed positive results when exposed to anger expression therapies for pain management. Affleck et al.'s (2003) earlier research indicated that because men are not traditionally exposed to techniques of expressing their feelings, therapy such as anger expression provides them with another valuable tool. Therefore, while men have an affinity to certain treatment techniques that will help them cope with their pain, there are other useful techniques that are not often used.

Rochlen, Whilde, and Hoyer (2005) report in their discussion of the *Real Men, Real Depression* campaign conducted in 2003 by the National Institute of Mental Health that men are commonly asked to explore their feelings through female dominated

treatments that are largely ineffective for men. Rochlen et al. (2005) suggest in their research on men diagnosed with depression, that there are four techniques that can be used to help men seek treatment in a manner that is appropriate for them: use 'real men' in print and video advertisements, utilize proper language that will build credibility, use the condition as a threat, and use language to elicit competition. These techniques were successful in promoting early diagnosis and treatment of depression in men possibly an important approach for men with other conditions that are likely to result in depression, such as AS (Rochlen et al., 2005).

As a result of pain and physical limitations associated with AS, depression is not uncommon (Gignac et al., 2008). Depression as well as the physical impacts of AS may also affect relationships; relationships are important for social and emotional functioning. In particular, involvement in intimate relationships can be challenging.

Intimate relationships. According to Statistics Canada (2009), the average age for men and women to be married was 30.2 and 28.2 years respectively. Given that with the majority of AS cases are diagnosed in their second decade of life (Chorus et al., 2003) this would indicate that the many people living with AS are diagnosed before they enter permanent stable relationships. Ward et al. (2008) found that being a spouse is an important social role that provides social support and can benefit physical and mental health outcomes for people living with AS. This important social institution appears to be less attainable for those with AS than the healthy population. Ozgul et al. (2006) asked 101 patients diagnosed with AS to complete the SF-36 survey and found that 26.3% of their cohort considered their disease an obstacle to marriage while Ward et al. (2008) reported a 50% greater chance of those with AS never being married compared to people

in the general population. For those who do marry, Ward et al. (2008) report in their research on 591 people living with AS across the United States, that people living with AS have a 30% increased chance of getting a divorce and men have a higher rate of divorce than women. This is in contrast to the earlier research by Feldtkeller and Lemmel (2004) in their review of over 1600 German patient surveys. They reported that divorce rates in their populations of men were not significantly different than their healthy counterparts.

Both Ward et al. (2008) and Feldtkeller and Lemmel (2004) agree that females with AS are more likely to be divorced or not married than females in the general population. Feldtkeller and Lemmel (2004) posit that this may be due to the way that they manage their disease or the social supports they require. Yim et al. (2003) found that women with AS showed significantly higher scores on the global distress scale than did men with the disease, as well women with AS showed significantly higher rates of depression than their healthy counterparts; depression may have played a role in their divorce rate as well. Related research shows that those with other types of arthritis also demonstrate a higher rate of depression associated with their disease (Pirildar, Muezzinoglu, & Pirildar, 2004; Wolfe & Hawley, 1998). None of the research explored the reasons for the higher divorce rates or why people remained single. Whether married or not, sexual relationships are important for those with chronic conditions as well as for those who are healthy (Pirildar et al., 2004; Yim et al., 2003).

Sexuality and sexual relationships. There has been a significant amount of research concerning AS and sexuality including sexual functioning. The literature has consistently reported that people living with AS have decreased sexual satisfaction

(Cakar et al., 2007; Pirildar et al., 2004; Yim et al., 2003). One of the challenges with this research is locating the factors contributing to this dissatisfaction although there is some indication that it may be the result of medications, pain, disability, and body image (Cakar et al., 2007; Dincer, Cakar, Kiralp, & Dursun, 2007; Pirildar et al., 2004; Yim et al., 2003). One contributing factor is sexual dysfunction, reported as being higher in people living with AS than the general population (Cakar et al., 2007; Dincer et al., 2007). Men with AS show lower levels of erectile function and overall sexual satisfaction than the general population (Pirildar et al., 2004). Pirildar et al. (2004) linked this decrease in satisfaction to morning body inflexibility that is associated with the disease in 70% of patients. Cakar et al. (2007) reinforced this by indicating that the type of joint involvement that is associated with AS (axial spine, shoulder, hip and knee) may make intercourse more difficult and may, as a result, decrease satisfaction. Pirildar et al. (2004) further mention that chronic diseases such as AS can cause deformities leading to issues relating to body image and depression.

Several studies have noted that people living with AS have high rates of depression which can, in turn, lead to issues of sexual satisfaction and confidence (Cakar et al., 2007; Pirildar et al., 2004). As well as impact on intimate relationships, some of the research suggests those with AS are concerned about becoming parents and the likelihood of passing along AS genes.

AS and genetics. Ozgul et al. (2006) report that there is a decreased birth rate in those with AS. They point to potential explanations as being the pain related to intercourse rather than fear of passing along AS genes, although this has not been clearly investigated. There is currently no known cause for AS; however, there is research

suggesting a genetic component increases AS susceptibility. What role genetics play and how important genetics are in diagnosis remain topics of debate (Brown, 2008; Hamersma et al., 2001; Ward et al., 2008). Researchers identified the HLA-B27 gene in the 1970s and while it is not exclusive to people living with AS, the gene is present in 90% the AS population (Brown, 2008; Pham, 2008). The HLA-B27 gene is present in the general population; however, only 5% will develop AS (Brown, 2008; Pham, 2008). This indicates a relationship with the gene, but it is certainly not a predictor of AS in the general population and, therefore, cannot be used as a diagnostic tool on its own (Brown, 2008; Pham, 2008) nor necessarily a predictor of genetic inheritance for AS. Recent studies have shown that in addition to the HLA –B27 gene, other genetic markers such as Interleukin-1 may also play a role (Pham, 2008) leading to some promising areas for future diagnostic approaches for both the person with AS and those wishing to become parents.

In a second line of research, Hamersma et al. (2001) examined the ability to predict disease severity based on genetics. In their research of 173 families with at least one member with AS, Hamersma et al. (2001) monitored sibling pairs, parent-child pairs, and first and second-degree relatives. Hamersma et al. (2001) used the BASDAI to measure disease severity and the BASFI to measure functional disability. Hamersma et al. (2001) found that “a strong genetic correlation was observed between the BASDAI and the BASFI . . . suggesting the possibility of shared determinants of these two measures” (p. 1398). This research suggests that certain genes may influence disease activity and functional disability differently (Hamersma et al., 2001). Hamersma et al. (2001) also found that “shared environmental factors play little role in determining either disease

activity measured at any one point in time or functional incapacity” (p. 1399). They found that disease severity was largely linked to genetics yet there are other studies that contradict their results (Brown & Wordsworth, 1997; Hamersma et al., 2001). Finding an underlying cause for AS may lead to some important diagnostic and treatment tools as well as providing those with AS information about their likelihood of passing on affected genes to their future children.

The majority of the literature for genetics and AS is clinical in nature and is primarily focused on the identification of genes that will help to predict onset or heritability. Genetic counselling is not a common theme; however, there is mention of predicting familial risk for ulcerative colitis (UC) and Crohn’s disease (CD) by Hemminki, Sundquist, and Sundquist (2010). Hemminki et al. (2010) examined a multi-generation register in Sweden for data from 1964-2004 and found that there is a relationship between UC and CD and the 32 autoimmune conditions they compared it with, suggesting genetic sharing. Since AS is closely linked, for some individuals, with UC and CD, these findings add an interesting component to the discussion of genetic inheritance. Additional investigation is required to determine whether people are making their decision not to have children based on genetics or some other factors.

As well as being an intimate partner and a parent, another important activity and role of young adults is their contribution to society through employment and the sense of independence it brings. Independence is considered an important component of people’s quality of life and, therefore, an increase in their dependence on others causes people to feel needy, helpless, incompetent and incapable (Gignac et al., 2000). This potential waning of independence is especially difficult when people are forced to leave the

workplace (Ozgul et al., 2006). A career change can impact relationships with family and friends, expectations for the future and self-confidence (Ozgul et al., 2006).

AS and employment. Arthritis is one of the leading causes for workplace disability and as with many other types of inflammatory arthritis, people living with AS need to make career decisions based on the severity of their disease (Chorus et al., 2003; Lacaille, White, Backman, & Gignac, 2007; Ozgul et al., 2006). AS may impact several different areas of work related life: productivity, work changes and leaving the labour force (Gignac et al., 2008; Ozgul et al.). Gignac et al. (2008) used a structured questionnaire to interview 349 people living with inflammatory arthritis or osteoarthritis in a four-part time series study and found that common issues of productivity were absenteeism and an inability to take on additional work. They found that more than 75% of AS affected participants experienced some type of work transition throughout the course of the study (Gignac et al., 2008).

Kobelt, Andlin-Sobocki, and Maksymowych (2006) report that Canadians living with inflammatory arthritis lose more than \$3000 each year due to lost time at work and these costs will increase based on age and disease severity. In certain cases, arthritis costs, between lost time and other expenses such as medications, can climb as high as \$30,000 each year (Kobelt et al., 2006). There are other non-financial challenges facing people with arthritis such as reluctance to talk about their arthritis, depression, and other emotional issues such as a fear about the future (Gignac et al., 2008; Lacaille et al., 2007). These can be equally stressful as they are often internalized in order to maintain appearances at work; people with arthritis are often reluctant to talk about their disease at work in an effort to blend in with the rest of the staff (Lacaille et al., 2007). Silence about

their condition is important to them so that they are not given preferential treatment or seen as a weak member of the team (Lacaille et al., 2007).

Other work transitions for people with arthritis, as discussed by Gignac et al. (2008), included changing jobs or leaving the workforce entirely. They found that 29.8% of the sample left the labour force and did not return whereas 7.2% left and returned at a later date. Other work transitions concerns were arriving late, inability to take on extra projects, problems with supervisors and coworkers, and arthritis-related work interruptions (Gignac et al., 2008). Each of these were common in more than 5% of the sample, some (arthritis-related work transitions) were much more common (30%). Ozgul et al. (2006) noted these work-related problems were not evenly distributed, they reported that people with higher education levels fared better at work and typically held professional positions. Ozgul et al. (2006) also noted that higher levels of education improved other areas such as exercise, knowledge of the disease, relationships and general health. In each of these areas people were better equipped to continue working or move on to another position because education levels were statistically significant.

Current Landscape of AS

It is evident that people living with AS require a timely and accurate diagnosis. This can be a challenge for health care providers based on variability in the disease severity (Shaikh, 2007) and the similar medical presentation to other arthritides such as RA (Symmons, 2002). The treatment for AS consists primarily of medication and physical activity (Sieper, 2009). One of the significant challenges outlined in the literature is the cost of these medications (McLeod et al., 2007). While physical activity may be more cost-effective than some of the pharmaceutical options, it has its own

barriers (Ariza-Ariza et al., 2003; Van Echteld, 2006). Finally, complementary therapies are increasingly accepted in the medical community as adjuncts to conventional management approaches. Some of the complementary therapies show benefit to people living with AS (SAA, 2010a) while others are questionable in their efficacy and others are potentially dangerous. It is clear that the clinical management of AS is well researched and is helpful in providing insight into the challenges facing those with arthritis in general and AS in particular. However, there was no published research I was able to locate that examined the patient experience of exercising or taking medications while living with AS, although a scan of the grey literature, including numerous patient forums and chat rooms for people living with AS showed that exercise and medications were key topics of discussion. This suggests that it might be an important emerging area for research. In addition to the physical effects of AS, and its management, other areas of research have included examination of some of the social and emotional impacts on people's lives.

AS is a disease of young men, and it affects all aspects of a young man's life both in intimate and other social roles. Quantitative studies show connections between men's help-seeking behaviours and employment, relationships and treatment choices (Addis & Mahalik, 2003; Ozgul et al., 2006; Ward et al., 2006). There is evidence that further research would be useful in understanding more in depth some of the factors that affect the day-to-day lives of these men. As Davis et al. (2009) indicated, the "2005 Summit on the Standards for Arthritis Prevention and Care . . . identified participation in family and societal roles as an important and meaningful outcome for people with arthritis" (p. 46). There is evidence indicating that men seek help differently than women and that

management and treatment approaches need to reflect this difference. Late diagnosis, the reluctance of men to seek health-related help, and the treatments associated with managing AS affect men's lives in a variety of ways. To understand better the challenges they are facing exploring the experiences of men with AS may be useful not only for the men themselves but also for their health care professionals. One of the challenges in engaging men with AS is finding those who may contribute to the research.

Challenges: AS Incidence and Prevalence

According to Statistics Canada (2010), there are more than 4.3 million people living with arthritis in Canada. That rate has fluctuated over the past number of years beginning at 4.4 million in 2003 and 2005, yet dropping to 4.1 million in 2007 (Statistics Canada, 2010). Men comprise less than 40% of all arthritis cases with the rate going as low as 37% in 2003 (Statistics Canada, 2010). Nova Scotia reported that 40.8% of all people living with arthritis in the province were men (Statistics Canada, 2010). This rate is higher than the average for the country.

Strong, Unruh, Wright, and Baxter (2002) in discussing epidemiology refer to incidence (the number of new cases of a disease) and prevalence (the number of existing cases) of a disease in a given population. Prevalence and incidence data for AS are sparse and variable (Bakland, Nossent, & Gran, 2005) because AS is most often not the primary disease being studied, but rather secondary to areas or research such as inflammatory bowel diseases (IBD) including CD. A search of multiple databases, including PubMed, Google Scholar, and CINAHL revealed that there were no articles relating to the prevalence or incidence of AS in the overall Canadian population. There are Canadian data of prevalence and incidence in research examining specific groups such as

Indigenous people in North America (Peschken & Esdaille, 1999), and those studying specific aspects of AS in Canadian men such as participation in social roles (Davis, Wong, Badley, & Gignac, 2009). In the Davis et al. (2009) research, prevalence was discussed in the introduction using European data, indicating the lack of general Canadian prevalence information. While there is other Canadian research about AS, the research has a medical/clinical focus which does not necessarily include prevalence and incidence of the condition. Given that there is a lack of prevalence and incidence data, additional sources from the United States (US), Europe and China were examined to provide a best estimate of these AS data in the Canadian population.

US prevalence data for AS are based primarily on a study conducted in Rochester, Minnesota where it was found that 129 per 100,000 Caucasians were found to have the condition (Carter, McKenna, Brian, & Kurland, 1979). However, these data were reported prior to the creation of the New York criteria for diagnosing AS, now considered the gold standard for diagnosing new cases of AS (Shaikh, 2007). The European prevalence of AS is reported as a range between 100 - 1400 per 100,000 (Boonen & van der Linden, 2006; Davis et al., 2009; Elyan & Khan, 2006), clearly a huge range. Despite the introduction of the New York criteria, the AS prevalence data reported by Carbone et al. (1992) and Carter et al. (1979) were also consistent with findings reported by Bakland et al. (2005) in the municipality of Tromso, Norway who found a rate of 410 per 100,000. According to Elyan and Khan (2006) as well as Boonen and van der Linden (2006), there is an accepted midpoint of 500 per 100,000 in their reported range of 100-1400 per 100,000.

Following introduction of the New York criteria, Carbone et al. (1992) conducted a further study into the Rochester, Minnesota population and found that the annual

incidence was 6.3-7.3 per 100,000. Bakland et al. (2005) also reported an annual incidence rate of 7 per 100,000 for the study period (20 years) in their research on two counties in Northern Norway. Therefore, despite the introduction of the New York criteria, both the incidence and prevalence rates were very similar from 1979 to 1992 (Carbone et al., 1992; Carter et al., 1979).

Despite the lack of Canadian incidence and prevalence data, there are local, provincial case data available in Nova Scotia via patient registrations in the Rheumatology Clinic at Capital District Health Authority (CDHA). CDHA is the largest health authority in Nova Scotia; it has the largest number of rheumatologists in the province, comprising approximately 80% of the clinicians (CDHA, 2010b). While the general Nova Scotian population has a large percentage of degenerative arthritis cases such as OA, the patients from the CDHA Rheumatology clinic are mostly diagnosed with inflammatory arthritides such as AS and RA. These CDHA clinical data do not capture the entire AS population in Nova Scotia; there are others, those who are treated by rheumatologists outside CDHA and others who are untreated or managed by another health care provider such as a family doctor. The CDHA Division of Rheumatology, based on 9 years of data from 2001 – 2009, reports an average 207 patients with AS each year (CDHA, 2010b). While the CDHA Rheumatology Clinic reports this patient load, the majority of people living with arthritis, and probably AS, who seek medical attention are seen by a family physician. Most of these patients remain in the care of a family physician despite some of who are referred to a rheumatologist (SAA, 2010c). While rheumatologists may diagnose the patient with arthritis and determine the plan for managing the disease, they may not be involved in the long-term management. Rather,

the rheumatologist will continue in an advisory or consultative manner to the family physician (SAA, 2010c). Therefore, it is likely that the caseload reported through the CDHA Rheumatology Clinic represents only a portion of those in the province who have AS. Using these data, extrapolating from Statistics Canada (2009) evidence, and based on Nova Scotia's population of approximately 944,000, there should be approximately 4500 people living with AS in Nova Scotia of whom 3000 are men. This is an estimate based on the agreed upon prevalence of 500 per 100,000 as indicated by European researchers (Boonen & van der Linden, 2006; Elyan & Khan , 2006). It seems reasonable to suggest that Canadian prevalence of AS is similar to that of other northern countries.

Xiang and Dai's (2009) review of the prevalence of rheumatic diseases in China found that prevalence rates for all rheumatic pain ranged from 11.6% to 46.4%. They found that the highest rates of rheumatic pain were found in northern China compared with the lowest rates occurring in Southern China. Xiang and Dai (2009) evaluated 41 surveys of rheumatic pain that were conducted throughout China. Of the 41 surveys, 14 indicated that the prevalence of rheumatic pain increased with higher latitude, suggesting that geographic positioning in Northern climates of China are a risk factor. Canadian researchers Lee, Helewa, Smythe, Bombardier, and Goldsmith (1985) also examined the relationship between Canada's northern climates in relation to prevalence rates and found that 60% of Canadians report some rheumatic pain. However, in countries closer to the equator, such as Pakistan, there is a reported rate of rheumatic pain of only 14.8% (Farooqi & Gibson, 1998). While the evidence implies that climate is the enabling factor for rates of rheumatic disease, it may be more closely linked with ethnicity or genetic background (Tolozza, Vega-Hinojosa, Chandran, Onate, & Espinoza, 2012). Yamada and

Yamamoto (2000), report that while the global prevalence for rheumatoid arthritis is approximately 1%, there are sub-populations with significant variations such as the Native American groups (2%) and Asian, southeast Asian and African populations (0.3%). These variations indicate that ethnic background or environmental factors such as infection rates may play a role in the prevalence of disease. Toloza et al. (2012) examined the burden of psoriasis and psoriatic arthritis among Peruvian Aborigines and found that climate, genetic background, and other risk factors such as trauma or infection impact disease rates. While future research will continue to explore the enabling factors associated with rheumatic disease, it is reasonable to conclude that a combination of environmental and genetic factors have an impact.

When thinking about the challenges of gathering good data about those affected by various illnesses, Singh and Strand (2009) report that the only way to fully capture all elements of the population and reflect the different levels of severity is to conduct a population survey. They also observed that population surveys may still result in a large margin of error. As they discuss, there will be people who believe they have a certain disease who will report it, when they have never been diagnosed. There will be people who cannot remember the name of their disease and they will not report anything. There will also be people who are not certain of their diagnosis so they may simply choose a disease that sounds familiar to them, inflating the rates for that illness (Singh & Strand, 2009).

Another of the challenges with capturing accurate data for the number of people with a given type of disease lies in the specificity of the criteria for diagnosis (Symmons, 2002). As Symmons (2002) discusses in her review of epidemiology of RA, the selection

criteria used to determine a firm diagnosis of RA are not specific enough early in the disease course in most individuals. While the patient may show signs of early inflammatory polyarthritis, it is unclear which disease type it will develop into over time. Many inflammatory arthritides show similar signs in early stages: RA, AS, Gout, Psoriatic Arthritis and others (Symmons, 2002). As Symmons has noted in the example of RA patients, many of them who later developed into RA did not present sufficient symptoms early in their disease to merit a diagnosis. This is a similar challenge that is faced for many inflammatory arthritides, including AS. Symmons points out that most research studies in RA indicate that “the date of onset of RA is said to be the date on which the criteria for RA are satisfied” (p. 710). Since there are always new patients waiting for a diagnosis, the epidemiological data are not accurate.

The uncertain number of AS cases both Canada-wide and in Nova Scotia might have presented challenges for a quantitative study; however given that this study used a qualitative approach, there was a sufficiently large pool from which to draw the anticipated 10-15 participants.

Summary

There are clearly some differences in the literature with respect to the accepted prevalence rates in a given population; however, there are sufficient data to estimate the number of people living with AS in Nova Scotia. It is possible that due to Nova Scotia’s northern climate the rates of AS and, therefore, the available population for the research, may be even higher than anticipated.

While there is significant research published about diagnosis of AS and its challenges, the efficacy of medications and their delivery as well as quantitative research

about the presence of depression and other psychosocial issues, there is a lack of evidence about the impact of these issues from the perspective of those affected. Lack of data about key topic areas such as help-seeking, pain treatment, physical activity and medication; indicate that there is still significant work to be done in this field of arthritis research. Men's experiences with AS are underrepresented in the AS literature. This current research project aims to provide some insight into these areas.

Chapter 3: Methods

This chapter discusses the research methods for this study including an overview of the proposed qualitative approach, the experiences and preconceptions of the researcher, and the detailed methods that were employed including a discussion of ethical issues.

A Qualitative Approach

Quantitative research approaches are most commonly used in the field of arthritis. As a method, quantitative research typically involves confirming or rejecting a hypothesis to a specific and measurable question (Patton, 2002). These quantitative hypotheses are relatively straightforward to prove or disprove as the outcomes are determined by numerical data and are highly effective at providing a detailed response to the research question (Patton, 2002). When performing the literature review for this research, it was clear that the majority of arthritis research is clinical in nature and, therefore, usually employed quantitative methods. Given that the benchmarks for AS and other types of arthritis are agreed upon clinical practice guidelines, or at minimum, standard tests that are used to monitor the disease, quantitative approaches have been preferred. While quantitative methods play a major role in arthritis research toward locating a cure, effective treatment, and even family planning, they are limited in their scope; they do not easily capture the individual personal experiences of their subjects. Qualitative methods, offer a different perspective to the research and enable different research questions to be asked.

Qualitative inquiry is not new in the field of research. While qualitative inquiry predates the 1960s, it was not until that time that it began to expand into the health care field (Cohen & Crabtree, 2008). While these methods are gaining recognition in health

care, they remain a small percentage of the arthritis literature. Beaton and Clark (2009) report that since 1996, there have been at least 15 qualitative studies in the field of knee OA. This literature review also found two articles on OA and one on RA that employed a qualitative approach (Edwards, Mulherin, & Ryan, 2001; Maly & Krupa, 2007; Petursdottir, Arnadottir, & Halldorsdottir, 2010) thereby supporting the observation that there are few qualitative arthritis studies.

Cohen and Crabtree (2008) argue that the scientific method (quantitative inquiry) is not always appropriate for studying people and that techniques such as “observation and interviewing would lead to a better understanding of social life in its naturally occurring, uncontrolled form” (p. 331). Creswell (2003), who is well known as a researcher and writer of both quantitative and qualitative methods of inquiry, indicates that neither approach is better than the other, but rather it is a question of which method will provide the best evidence to support the research question. Qualitative research presents the ‘how’, ‘why’ and ‘what’, which require an investigation of complexity, process, content, or issues that are not easily quantifiable” (Beaton & Clark, 2009). As one of the questions for this research is concerned with the barriers and enablers to health care for people with AS, understanding the complexity of issues in a given situation is important to answering the research question.

According to Cohen, Kahn, and Steeves (2000), the term ‘qualitative’ is a broad category of research that includes specific subgroups of research such as ethnography, grounded theory, and phenomenology. A qualitative approach is particularly important when seeking to understand people’s experiences, the meaning of the experiences, and the environment from which they come (Patton, 2002). Qualitative approaches allow for

more direct contact with informants and greater understanding of a particular issue. As well, qualitative approaches analyze the findings in their proper context (Creswell, 1998; Patton, 2002). Qualitative methodologies allow for the inclusion of multiple realities, even when they may contradict one another (Halldorsdottir, 2000). The reality is constructed between the interviewer and the informant and represents the reality for that particular point in time. There are no “absolute” truths, but rather, they are subject to the context of the environment as well as the time (Halldorsdottir, 2000). Qualitative results are not generalizable, but rather are applicable across groups based on their relational quality.

Qualitative designs offer participants the opportunity to explain their answers and, in some cases, allow the researcher to ask additional questions to those that were originally planned. This is beneficial if the interview guide is not drawing out the topic area of interest (Fontana & Frey, 1994). Despite the preponderance of quantitative research in the arthritis literature there are some examples of qualitative research that have examined patient experiences.

There is a paucity of literature on understanding the patient experience of living with AS; however, there are several qualitative arthritis studies that examine patient experiences with OA of the knee (Beaton & Clark, 2009; O’Neill, Jinks, & Ong, 2007). Beaton and Clark (2009) showed how the shift in knee OA research toward qualitative methods provided greater understanding for the deeper issues that relate to the disease. In their meta-analysis of OA qualitative research, O’Neill et al. (2007) explored “the factors that influence the decision making process of [total knee replacement] surgery” (p. 1). The richness of the data in all 10 articles in the study could not have been provided

through quantitative methodologies. Employing a qualitative approach allowed the researchers to understand the experiences of people with knee OA and why they did or did not choose to have total knee replacement surgery. Maly and Krupa (2007), in studying the experiences of people with knee osteoarthritis (OA), described their phenomenological approach as important in providing “an understanding of the internal or insider’s perception [as] health care professionals will lack the contextual perspective necessary to identify what implications of disease are most important to people with knee OA” (p. 1423).

Using the OA research as a guide, this project was focused on understanding the experiences of young men with AS. Given that the intention was to gather deep, rich data, through detailed questions about their lives, qualitative methods were the most appropriate.

A phenomenological approach. Within the field of qualitative inquiry there are many different approaches that can be taken such as grounded theory, ethnography, and phenomenology (Beaton & Clark, 2009; Creswell, 2003).

Grounded theory is focused on the development of a theory that is “grounded in the words and actions of those individuals under study” (Goulding, 2004, p. 296). Furthermore, grounded theory encourages the researcher to begin the research process without an extensive review of the literature. Given that I was not focused on the development of a theory, but on understanding the experiences of these young men, this approach was ruled out.

Ethnography is concerned with the “prolonged participation within a specific culture or sub-culture” (Goulding, 2004, p. 299). This process can sometimes result in

full immersion into a specific cultural group. Finally, Ethnography aims “to explain the ways that culture constructs and is constructed by the behaviours and experiences of its members” (Goulding, 2004, p. 299). Since I was not immersing myself in the culture and did not have prolonged exposure to the cultural norms of a particular group, ethnography was not the appropriate choice. Furthermore, while I knew that cultural factors might arise in the research, they were not the focus of this study; my focus was on the day-to-day experiences of young men with AS. Given that my research questions were concerned with the “meaning” of the lived experience, a phenomenological approach seemed most appropriate. Phenomenology explores the “meaning of a phenomenon in a group of people within the context of their lived experiences” (Beaton & Clark, 2009, p. 109). The outcome is the understanding of the lived experiences of the individuals rather than the creation of a theory or confirming one (Beaton & Clark, 2009).

Phenomenology can be used as a research philosophy and as a methodology (Cohen et al., 2000; Halldorsdottir, 2000; Van Manen, 1990). This research used phenomenology as a methodology. Additionally there are different branches of phenomenology, some arising from linguistic approaches and others based in the traditions in psychology. While similar in the broadest contexts, there is much argument within the field of phenomenology about which approach is most effective. This argument affects both the philosophical and methodological approaches. On a philosophical level, phenomenology is a mode of thinking where the lived experiences and their meanings are believed to be the core of a person’s belief system. As a methodology, the various phenomenological ideals are applied to conducting research in a systematic manner. This thesis does not discuss phenomenology as a philosophy, but

rather focuses on it as a methodology for collecting, understanding, analyzing, and reporting the data.

Cohen et al. (2000) examined the hermeneutic phenomenological approach that describes phenomenology as the study of phenomena. They discuss the concepts of the *noumena* and *phenomena* defining the noumena as “the things themselves, the physical, unchanging, and concrete things as compared to the phenomena, our experience of the things” (Cohen et al., 2000, p. 3). Phenomenology recognizes that each person is unique and seeks to study that uniqueness to understand the personal perspective of the informant with the desired outcome being uncovering themes within the research (Cohen et al., 2000).

In the field of hermeneutic phenomenology, the approach taken here, in Canada, Max van Manen is considered one of the pioneers (Cohen et al., 2000). Van Manen’s 1990 book titled *Researching Lived Experience*, highlights several key components to hermeneutic phenomenology. He points out that hermeneutic phenomenology is the study of lived experiences and the explication of phenomena as they present themselves to consciousness. Van Manen (1990) states that the experiences of an individual, “whether real or imagined” are true to that person and are ‘real’ as they exist in the person’s consciousness (p. 9). Van Manen (1990) states that “to be conscious is to be aware, in some sense, of some aspect of the world” (p. 9). Since conscious experience is something the informant had to have experienced personally and “a person cannot reflect on lived experience while living through the experience . . . thus phenomenological reflection is not introspective but retrospective” (van Manen, 1990, p. 10). Van Manen’s work in hermeneutic phenomenology provides context for the concepts and ideals of this

approach. It is van Manen's, as well as other phenomenologists, belief that the researcher must begin the research with an open mind and allow the experiences of the informants to guide the results and direction for the research.

There are various approaches to the practical implementation of phenomenology. To gather and understand these experiences, The Vancouver School of Doing Phenomenology offers a step-by-step approach (Halldorsdottir, 2000).

As described by Halldorsdottir (2000) "'The Vancouver School of Doing Phenomenology', which is an interpretation of phenomenological constructivist/interpretivist philosophy and its use as a research methodology for the human sciences, was inspired by the work of Joan M. Anderson at the University of British Columbia, Vancouver, Canada" (p. 53). The Vancouver School of Doing Phenomenology (The Vancouver School) was strongly influenced and shaped by the work of Schwandt, Spiegelberg, and Ricoeur (Halldorsdottir, 2000). The Vancouver School took the work of Spiegelberg and developed 12 methodological steps.

In order to fully understand the development of the Vancouver School it is important to return to the roots of the phenomenological philosophy/methodology that began with Edmund Husserl and Martin Heidegger. They are credited as the key founders of phenomenological philosophy and methodology that desired to understand the meaning of human phenomena (Halldorsdottir, 2000). Husserl was a teacher and mentor for Heidegger, who in later years diverged from some of Husserl's philosophical views of phenomenology. Husserl believed that conducting phenomenological research required a "bracketing" of preconceptions on the part of the researcher. Bracketing, according to Husserl, implies that "prior knowledge could be suspended and set aside so that fresh

impressions could be formed about the phenomena without the interference of these interpretive influences” (LeVasseur, 2003, p. 409). However, Heidegger and subsequent phenomenologists disagreed, attributing the strength of phenomenological research to the construction of reality between the researcher and informant with full acknowledgement of preconceptions or biases. The ideas of Husserl and Heidegger were further expanded by subsequent philosophers who concluded that the interpretation of the meaning was critical to understanding the phenomena especially as it reflected the interaction between the research participants and the researcher.

In order to carry out phenomenological research various approaches have been developed. In particular, The Vancouver School provides a step-by-step approach informed by the developments in phenomenology provided by Spiegelberg, Ricouer, and Schwandt.

Herbert Spiegelberg, a phenomenologist from the mid-20th century was instrumental in collecting and synthesizing the history of the phenomenological movement in his book titled *The Phenomenological Movement: A Historical Introduction*. Spiegelberg (1965) began to describe the methodology of conducting phenomenological research. He originally developed a seven-step process that began with selecting dialogue partners (research participants) and concluded with writing the findings (Halldorsdottir, 2000; Spiegelberg, 1965). These steps have been adapted for use in the Vancouver School.

Paul Ricouer has played a critical role in the field of phenomenology exploring the use of hermeneutics and its application. Ricouer believed that phenomenology, as it was originally proposed by Husserl in the early 20th century, was undeveloped in its

approach and philosophy (Ricouer, 1975). Ricouer believed that “there exists between phenomenology and hermeneutics a mutual belonging” (1975, p. 85). Ricouer believed that the connection between hermeneutics and phenomenology was foundational, indicating that “phenomenology is the place where hermeneutics originates” (Ricouer, 1986, p. xiii). According to Ricouer, hermeneutics “designates the work of explication” (1975, p. 89) concerning itself with the interpretation of texts in phenomenology. Ricouer’s beliefs about the interpretive approach to phenomenology became a key influence on the development of the Vancouver School.

Tom Schwandt, a more recent phenomenologist than Spiegelberg and Ricoeur, also believed that a constructivist and interpretivist approach was important in phenomenological research. In his contribution to Denzin and Lincoln’s *Handbook of Qualitative Research* (1994), Schwandt proposes that “a constructivist view causes the researcher not only to treat his or her own observations as constructions but to regard reader conceptualizations as their own constructions” (p. 61). Schwandt’s influence in the Vancouver School was his view that in using a constructivist and interpretivist approach the inquirer must attend to his/her “own self-reflective awareness of his or her own constructions and to the social construction of individual constructions” (Halldorsdottir, 2000, p. 53). Schwandt, and thus the Vancouver School, believes in multiple constructions or realities that may or may not always coincide.

Both van Manen, and the Vancouver School assert that the data are insufficient to report on their own and that the researcher must make sense of it in partnership with the research participants who act as co-researchers (Halldorsdottir, 2000). While it is important to remain open to what is being said by the informants in an effort to

understand their perspective, perspective is not all that is required. Constructivism is at the core of The Vancouver School's philosophy, the belief that knowledge is not simply acquired, but rather that it is constructed (Halldorsdottir, 2000). According to Guba and Lincoln (1994), a constructivist views the world as a series of different meanings depending on the person or group who is being researched. As the target population changes from one research project to the next, so do the realities or constructions of the world. The realities change with the target population as each group views the world slightly differently. Neither is right or wrong; they each hold their own perspective that gives them meaning in their environment.

This construction of reality is unique to each individual and it is, therefore, possible to have multiple realities at the same time, each with its own merit (Halldorsdottir, 2000). The Vancouver School seeks to understand the lived experiences of the research participants (also known as the informants or in the Vancouver School the dialogue participants) within the context of their constructed reality.

Research Design

Proper research design is critical to achieving solid results (Madsen, 1992). Given the purpose of the study was to explore the experiences of young adult men with AS, qualitative techniques were employed to be consistent with answering the research question. The following sections describe and discuss the overall methods using the 12 steps of the Vancouver School and its structure (Halldorsdottir, 2000).

1. Selecting the dialogue partners.

Sampling. Qualitative research states that bias, usually referred to as preconceptions, assumptions, and experience to eschew quantitative terminology, is a part

of the constructed reality between the researcher and informant. Phenomenology specifically, and qualitative research generally, selects purposefully from the study population, unlike the random selection used in quantitative research, to acquire information rich cases that can be explored in depth to develop a greater understanding of the specific population (Patton, 2002). Creswell (2003) indicates that “the idea behind qualitative research [and phenomenology] is to *purposefully* select participants . . . [who] will best help the researcher understand the problem and the research question” (p. 185). Creswell observes that qualitative research requires a level of homogeneity in the sample to ensure that the findings are comparable among informants although, as others have noted, it is important within the sample to provide a range of experiences (Sandelowski, 2000). This phenomenological research design used purposeful sampling to acquire its informants.

Where purposeful sampling seeks to identify the information rich cases, intensity sampling is concerned with finding the “cases that manifest the phenomenon of interest intensely” (Patton, 2002, p. 234). Intensity sampling was used in this study in conjunction with purposeful sampling to identify information-rich informants. This research had also planned to use snowball sampling if needed. Patton (2002) describes snowball sampling as the process of asking well-situated people to refer the researcher to potential informants. Snowball sampling was employed during each interview by asking the informants if they knew any other men with AS who fit the research criteria, but no further informants were identified.

Sample size. According to Patton (2002), qualitative inquiry generally, and phenomenology specifically focuses on smaller sample sizes rather than the larger

numbers generally associated with quantitative research. In a qualitative study the focus of the sample must be on the depth of the research rather than the breadth (Patton, 2002). Lincoln and Guba (1984) state that the sample size should be determined based on reaching the point of redundancy. Simply put, redundancy is achieved when no new information arises in the research. Creswell (1998) posits that a sample size for qualitative inquiry should be somewhere between 10 and 25 participants depending on the constraints of time, availability, and finances. Petursdottir et al. (2010) provide an example of research in the field of arthritis using a phenomenological approach where they conducted interviews with 12 individuals. Other research that employs a phenomenological approach uses between 5 and 20 participants depending upon the purpose of the research (Creswell, 1998). While the original intent of this research was to recruit between 10-15 informants, there were some challenges in recruitment. After seven informants were recruited the other potential informants could not be contacted or did not respond to requests to participate. As a result, the thesis committee agreed that a minimum of seven informants with a minimum of six follow-up interviews would be sufficient for the research.

A sufficient sample size in qualitative research is commonly determined when redundancy in the data has been achieved; that is, no new themes emerge (Creswell, 1998). In this research project, saturation in the data was achieved after the sixth informant was interviewed; no new themes emerged from the seventh informant.

Dialogue partner characteristics: Inclusion/Exclusion criteria. An important part of any research project is to define the target population. AS is a disease that primarily affects young men, and as previous research has noted there are often

significant differences between the experiences of men and women with chronic conditions (Sieper, 2009). As mentioned in the first two chapters, the focus of this research was on young men's lived experiences with AS and the barriers that they encounter or perceive when accessing health care. As previously stated in the literature review, men have significant differences from women with respect to their pain levels, emotional health, and help-seeking behaviours (Addis & Mahalik, 2003; Unruh, 1996; Yim et al., 2003). In order to ensure a greater likelihood of comparing these results to existing literature, only men were included in the research. Patton (2002) points out the benefits of sampling outliers and extreme cases, therefore I was open to recruit a wide range of young adult men with AS (Chorus et al., 2003).

The arthritis research has not had much debate about the age range that might be considered "young adulthood"; however, there has been extensive discussions in the psychosocial cancer research literature. Much of this cancer research classifies young adults as those between the ages of 18 and 39 (Zebrack, 2009). This age range parallels the most common age range for a diagnosis with AS (Chorus et al., 2003; Sieper, 2009). Informants under the age of 18 years were not included for this research in part because they are mostly considered part of the pediatric population in Nova Scotia and might not have insights into the life decisions regarding family and career that are important elements of this study. Informants under age 18 were also excluded from this research based on the experience of Zebrack (2009) and the young adult literature that characterizes adulthood beginning at age 18. Therefore, men aged 18-39 at the time of the study were chosen for this research project. The sample informant's age range also ensured a greater likelihood of them recalling the entire spectrum of their disease, from

pre-diagnosis to the current day.

Inflammatory arthritis such as AS is difficult to diagnose and, therefore, informants had to be diagnosed with AS by a rheumatologist to be eligible for the research (Sieper, 2009). Given the difficulty of diagnosing AS and the similar presentation of other types of spondyloarthritis (specifically Psoriatic Arthritis), informants were required to have a primary diagnosis of AS and not Psoriatic Arthritis. Each informant was asked to confirm he was diagnosed with AS by a rheumatologist prior to the interview.

Length of time living with AS was also an important factor in this research. As this study is also concerned with barriers to services, it was important that people who were newly diagnosed be excluded from the study. Informants had to have been diagnosed for at least one year to ensure that they have had time to experience various aspects of AS including having engaged with the health care system. The richness of the data is based upon the lived experiences of the research informants and it was, therefore, important that they have the opportunity to spend time accessing services.

Finally, all informants had to reside in Nova Scotia at the time of the study and be English speaking. All informants were screened by me to ensure they could complete the interview in English.

Informant recruitment. Purposeful sampling for this study began with the observation that many of the AS population are diagnosed by a rheumatologist with whom they have regular appointments to monitor the progression of their disease (Sieper, 2009). Therefore, rheumatology clinics were a logical recruiting ground for study informants. As the SAA (2010a) notes, people who are in regular contact with their

rheumatologist are more likely to have moderate to severe disease rather than those who would be managed by their family physician. Given these observations and the need for having dialogue partners who had experience with the phenomenon, I concluded that the population who attends the rheumatology clinic was more likely to consist of cases that would be information-rich. With this in mind, I approached the CDHA Department Head of Rheumatology, with a letter explaining the proposed research and seeking permission to advertise for informant interest. Through one of my committee members, a rheumatologist at CDHA, I asked permission to work with the rheumatology research assistant to locate appropriate informants from the rheumatology clinic database. Each rheumatologist granted permission and the research assistant contacted men from the clinic database, inviting them to participate in the research study. The research assistant provided background on the project to the potential informants verbally over the phone based on a recruitment letter that had been provided by me (Appendix A). Once informants agreed to be contacted, the research assistant provided the names to me, the principal investigator.

While the clinic database contained a sufficient number of patients to meet the sample size for the research, the research assistant was not able to contact some of them and others did not consent to be a part of the research study. If all of the patients who indicated interest to the research assistant could have been contacted or had agreed to participate in the study, the research would have exceeded the original plan of 10-12 informants. Given that there was a contingency to employ snowball sampling, it did not appear to be necessary to expand the scope of the recruitment to the private rheumatologists who work outside of the CDHA clinic.

As well as direct recruitment through the Rheumatology Clinic list, posters were placed throughout the CDHA Rheumatology Clinic waiting rooms and examination rooms. The posters had my name, contact information and an overview of the proposed study (Appendix B). Contact information included my private cellular telephone and Dalhousie University email account. Only I, the researcher, answered the telephone number where there was a voice mail account for potential informants to leave a message if I was unable to answer. I was the only one with access to the email and voice mail account. Rheumatologists were invited to refer their patients to the study by encouraging them to contact me. For patient confidentiality reasons the rheumatologists did not contact me directly with names of potential participants and contact information. Rheumatologists' admitting staff and nurses were also encouraged to invite patients to take part in the study but were also constrained by patient confidentiality regulations. Finally, once those recruited agreed to participate in the research, they were asked to selected pseudonyms for themselves.

2. First, there is silence.

Reflection: The literature. In conducting phenomenological inquiry, the researcher begins by reflecting on the phenomenon of interest (Halldorsdottir, 2000). To accomplish this, I began by reading extensively about arthritis, inflammatory arthritis and the experience of young men and women with arthritis, to locate gaps in the literature for this project. As is evident in chapter 2, I prepared myself with an in depth examination of the published research with particular attention to phenomenological literature related to the topic. I was able to locate only a few phenomenological studies in the arthritis field.

O'Neill et al. (2007) highlighted several examples in their meta-synthesis of knee

OA research that used a phenomenological approach. Petursdottir et al. (2010) reported in their research of 12 individuals with OA, that they employed the phenomenology approach of the Vancouver School to better understand the facilitators and barriers to exercising. They used such an approach “because it has proven useful in increasing knowledge and deepening understanding of human phenomena within the various fields of health care” (Petursdottir et al., 2010, p. 1016). Petursdottir et al. (2010) indicated that there are many internal and external factors that influence people living with OA on whether they engage in exercise activity or not. Their research reports that it is not whether to exercise or not, but rather “how, how much, and under what circumstances” (Petursdottir et al., 2010, p. 1023). These examples show how phenomenology is used to understand barriers to using health care services. The above literature demonstrated that there is precedent for using phenomenology in the field of arthritis, even more relevantly to provide understanding of the lived experiences of the people with arthritis. But there was no work related to young men and their experiences with ankylosing spondylitis.

Reflection: Researcher orientation. Given that the researcher’s perspective is a significant part of phenomenological research, as van Manen (1990) says, making the researcher perspective visible is important. As part of the Silence, I reflected upon my research orientation, my view of bracketing my preconceptions, and my experiences as they related to conducting this research project.

For this research, I employed a constructivist knowledge claim. Epistemologically, my informants and I each brought certain experiences and opinions to the interview. This unique blend of thoughts and experiences constructed the reality between us. Guba and Lincoln (1994) point out that the interviewer and the interviewee

are “interactively linked so that the ‘findings’ are literally created as the investigation proceeds” (p. 111). As a result of this interaction, phenomenological researchers consider their researcher participants as co-researchers or informants “because they inform us about their experience” (Cohen et al., 2000, p. 12). Throughout the interview process, I experienced different circumstances with each informant and also constructed new realities with them.

Creswell (1998) points out that all researchers bring a certain level of bias, and their assumptions, or prejudgements and preconceptions with them to the interview and that there has to be a method for acknowledging or setting aside these preconceptions. Agreeing with Heidegger, Schwandt, whose work informs the Vancouver School, I believed that bracketing was not possible noting that the interaction between the informant and the researcher constructs the reality for the discussion (Halldorsdottir, 2000). Because the researcher is the primary instrument who collects and analyzes the data, it is necessary for the researcher to disclose his/her biases (preconceptions) to the informant (or co-researcher) in an effort to be transparent (Halldorsdottir, 2000). Practically speaking, as part of using a phenomenological approach (and most qualitative approaches) making the researcher visible means discussing his or her role in the first person, and acknowledging that the researcher is important to the research as is the informant. While I made every attempt not to impose my beliefs on the participant, I did actively engage in the dialogue making visible my own experiences and preconceptions both at the beginning of each interview and also when appropriate throughout the interview. In keeping with these principles, I also kept a reflective journal to remind myself how I might potentially have influenced the process and data interpretation. As

well as these processes I also examined my previous experiences with arthritis both professionally and personally to attempt to open myself to viewing the dialogues with as few preconceptions as possible. What follows is an overview of my research orientation and experiences as they relate to conducting this research project.

As a former employee for over three years at The Arthritis Society, I have had extensive interactions with patients, rheumatology department staff and physicians, and members of the research community across Canada. My brother and my wife both have a diagnosed form of arthritis, with my brother having a mild case of AS. I am, therefore, aware of some of the physical as well as emotional impacts of arthritis. My uncle has been living with Rheumatoid Arthritis since the 1970s and has had extensive challenges with medication access and surgery. As a result of these experiences I shared some of my assumptions with my supervisor and also recorded them in the transcripts as notes. My preconceptions about this research were focused on areas such as pain and how it impacted day-to-day experiences in personal and work life as well as the impact it had on social relationships, specifically intimate relationships such as marriage. I believed that people with AS would have greater difficulty in managing personal relationships.

3. Participating in a dialogue: Collecting the data. Prior to participating in the dialogue, I reflected upon my skills as an interviewer, given that my ability to engage in the dialogue was critical to ensuring that the purpose of the research could be achieved. I spoke with my advisor about my ability to conduct interviews and my comfort level handling emotional issues that may arise. I practiced asking my research questions prior to the first interview with my wife and my supervisor. I also spent a lot of time preparing and reviewing my interview guide, phenomenology and the literature review chapter I

had written. This process ensured that I was able to be comfortable entering into the research as well as open to whatever I heard from the informants. As Halldorsdottir (2000) describes, I entered into a reflective silence prior to beginning the interviews. Ultimately, I became more skilled as the interviews proceeded and I reviewed the transcripts with my supervisor.

As part of the reflective process I also examined the role of my informants as co-researchers. As previously discussed, there is much discussion in the qualitative literature referring to the research “subject” as defined quantitatively, as inappropriate. Hallisdottir (2000) discusses the research participant as a co-researcher rather than a subject of the research noting the participants’ contribution to creating knowledge through the dialogue. Others acknowledge this co-construction by referring to the co-research as an informant or as a dialogue partner. I chose to use the term informant for my participants.

After I received the names from the Rheumatology Clinic assistant and prior to participating in the dialogue (interview), I contacted each informant by telephone, and at times, was able to speak to him on the first telephone call, while other times I left a voice mail message for him to call me back. Once I was able to speak to each informant and he agreed to participate in the study, I scheduled a time to meet with him at a location of his choosing. I offered to meet him at his residence or at a neutral location that was quiet such as an office or a room at the Dalhousie campus. The first interview was booked within two weeks of the initial phone call at the informant’s first available time.

Participating in the dialogue occurred through face-to-face interviews. As indicated by Cohen (2000), face-to-face interviews offer the researcher the opportunity to not only listen carefully to the informant’s responses but also to observe the non-verbal

cues that help to construct the reality and provide insights into the experience. All interviews were semi-structured. While not usually associated with a phenomenological approach to inquiry, a semi-structured interview allows for a series of questions to be prepared in advance, but also allows the researcher adequate freedom to pose other questions during the interview to explore areas that need further clarity or are of particular interest (Creswell, 1998). I used semi-structured interviews (see Interview Guide - Appendix C), not only for the reasons stated above, but also because this was my first interviewing experience. The structure helped to keep me focussed on the research question. All interviews were audio recorded and transcribed verbatim.

No other person accompanied informants during the interview as research has shown that this can limit the quality of the data (Seidman, 2006). Interviews were not held in a public location such as a coffee shop for confidentiality reasons and to maintain proper audio recording quality. The first interviews were approximately 60 minutes in length, although they ranged from 45 – 80 minutes.

Following the interview, a verbatim transcription was made of the interview with the exclusion of vocal fillers. Verbatim transcription is important as it ensures rigor as well as provides informants with the opportunity to clarify the interview content and to clarify my perceptions (Sandelowski, 1994). I transcribed all of the interviews with the exception of three, which were transcribed by an outside person who signed a confidentiality form (see Appendix D). From the verbatim account a general summary of the interview was prepared, reviewed by my advisor, and sent in by email to the informant, a process that took approximately four weeks.

A follow-up interview was arranged for approximately 30 days after the transcript

was sent to the informant. This second interview was approximately 30 minutes in length, depending upon the informant, with the purpose of verifying the accuracy of the first interview transcription, allowing the informant to add information, and to allow me to follow up with any additional questions that arose from his first interview. During this second interview, informants were given the opportunity to retract comments or provide further explanation for anything that arose in the transcription. To ensure the accuracy of the data, all informants in the research were required to be available following the interview process for clarification via phone or email; however, this was not necessary.

Interview guide. Semi-structured interviews were used to collect the data from the informants in the research. The purpose of this guide was to provide me with a reference tool for the interview in the event that the informant required additional prompting.

Seidman (2006) indicates that caution be used with respect to interview guides.

Phenomenological inquiry requires the researcher to understand the experiences of the informants in the context of their life and their reality. If the researcher is focused on the interview guide as a survey that must be completed, the essence of this approach will be lost. While I created an interview guide, all of the questions did not need to be asked. It was only to be used to assist informants who needed additional prompting to discuss their experiences and to remind me about the key concepts important to the interview. The interview guide was structured such that the initial questions were very general and provided the opportunity for the informant to relay as much as he wished. Additional questions were posed for the main categories of inquiry found in the literature review including diagnosis, treatment, physical activity, complementary therapies, quality of life, help-seeking behaviours, pain treatment, intimate relationships, sexuality, genetics, and

employment (see Appendix B for the full interview guide). The interview guide was not to be the sole source of questions during the interview process. During the dialogue informants made comments and raised issues that I had not noted in preparation for the discussions.

4. Sharpened awareness of words. Although reported here as a separate process, the data collection and data analysis, after the first interview, were conducted concurrently. Interviews took place while I was transcribing and analyzing previous interviews and, in an iterative process, findings from the previous interviews informed and shaped the dialogue in subsequent interviews.

The research interviews and other data were analyzed using interpretive phenomenological techniques. The hermeneutic circle is commonly used to structure the analysis in phenomenology (Cohen et al., 2000). The hermeneutic circle is not as process-driven as other qualitative techniques such as those used in grounded theory where there are clear steps to the process. The hermeneutic circle uses a process whereby the researcher alternates reviewing most detailed, local data followed by the most global, general data (Gadamer, 2004). This process “requires the investigator to consider the meanings of the smallest units of data in terms of ever-increasing larger units of data and vice versa” (Cohen et al., 2000).

Cohen et al. (2000) indicate that the researcher begins the data analysis process with the first interview through the construction of field text, of which the researcher cannot help but read and, therefore, analyze and interpret. I analyzed the research through a series of steps. I began by debriefing the interviews with my transcriptionist, and at times, with my supervisor. Since I transcribed all of the interviews with the exception of

the first three, I found that the line-by-line attention to the transcription was very useful for noticing themes, noting inflections in the tone of the discussions and highlighting interesting phrases. I made notes in the margins of the transcripts not only about the key phrases but also my observations about verbal (tone and emphasis) and non-verbal expressions.

After the transcriptions were completed, I read the texts repeatedly in order to note the elements that would begin to construct the themes for this interview. I would closely examine the responses to the questions and look for individual nuances that were different from the other interviews as well as components that might be similar. Following this intensive reading, I wrote a summary and during this summary I was able to note the elements of the interview that stood out and other areas I might have missed.

5. Beginning consideration of essences: Coding. I began consideration of the essences by using post-it notes of differing colors to note similar expressions, ideas and key concepts on individual interviews as I was reading each one. These were posted in my work area of my home and were rewritten and reorganized many times over several weeks. As a result of reflecting upon these various categories, I was able to see themes that emerged from each interview. This process was helpful in becoming closely acquainted with the content as is required in a phenomenology.

After each transcription, I discussed the contents with my supervisor and we compared points and themes arising from each of the men and looked for similarities with the others. Following these discussions, I developed additional questions to ask in the follow-up interview. These questions were very helpful during the second interview as they provided clarity to key areas and an opportunity to ask about topics that arose with

the other informants.

After several iterations of the themes I met with my supervisor and we discussed some other potential structures for the themes. In this phase I was focussed on identifying the themes and their meanings for the experience.

6. Constructing the essential structure of the phenomenon for each case.

Following the identification of some of the themes I developed a summary of each dialogue for individual informants. The summaries were designed to reflect the key elements of each interview for verification by the individual informants.

7. Verifying the case construction with the informant. After the first interview, I created a summary of the interview and sent it to the informant for review. I asked the informant to review this prior to the follow-up interview for accuracy of both facts and perceptions. The informant was encouraged to send any corrections or additions to me via e-mail or to share the clarifications at the second interview. The follow-up interview was held within three weeks of the summary being sent to the informant. The data from the second interview were added to the first to create a clearer understanding of the informant's experience.

8. Constructing the essential structure of the phenomenon from all cases.

Following the same procedure as I did in coding the individual interviews, to construct the essential phenomena for all cases, I used a number of processes such as colored sticky notes, whiteboards, printed copies of text and discussion with my supervisor. The colored sticky notes provided me the ability to consider the potential key themes that arose from each informant and how they were connected to the larger group. I was able to make margin notes about which informants were connected to each theme and sort them in

different ways to consider the larger key themes that were arising. I used whiteboards to capture key thoughts as I began writing the results and discussion chapters. In writing the text, new thoughts, ideas and connections between the informant's individual data became clear. It was important for me to have the ability to capture these thoughts when writing. Several times throughout the process I was restructuring the organization of the data and key themes. Throughout this process, I used the printed transcripts to cut and paste into sections so I could physically see the headings and how they might be reorganized. I was in regular contact with my supervisor throughout the data analysis and writing phases. We often discussed the meaning behind the data and how it was best interpreted to ensure the voice of the informants was evident. These processes were essential to ensuring the analysis of the overall structure of the phenomenon was clear.

9. Comparing the essential structure with the data. The essential structure of the phenomenon was compared with the data through quotations from the informants. Once the key themes were identified, I re-read the transcripts and summaries from each of the informants again and identified quotes that could be used. After all pertinent quotes were identified I integrated them into the text where appropriate. Initially, I used multiple quotes for each theme to ensure the quote was appropriate and fit with the key theme. Over time, I selected the quotes that best represented the text and removed the others that did not fit with the theme. I also kept a file for those quotes that did not fit with the themes that were emerging.

10. Identifying the over-riding theme. Throughout the collection of individual cases, I began to see some consistency between the informants around one particular topic. After completing the individual case constructions, I was able to identify an over-

riding theme to the research. I discussed this with my supervisor as well as key contacts within my school who had expertise in this area. After much consideration of the key themes and their interaction with the over-riding theme, I determined that this was representative of the informant's voices.

11. Verifying the essential structure of the phenomenon with some of the co-researchers. After considering this step and discussing it with my thesis committee, I chose not to complete this step given the time constraints of my Master's thesis. My Thesis Committee supported this decision.

12. Writing up the findings. The process of writing up the findings took place over a few months and involved constructing a multi-voiced text that was representative of the informants in this research. When constructing the text, I used the informant voices wherever possible to ensure that their stories are related to the reader. I created a narrative to link together informant quotes and provide context for their stories. This process helped me to understand what I had heard from the informants and interpret the text appropriately. This interpretation of the informant's voices was verified with my supervisor and my committee members.

Goodness/Trustworthiness of the Research

Most AS research is clinical in nature and, therefore, is focused on quantitative methods that measure the quality of the research, such as reliability and validity. Quantitative methods are accepted in the research communities when the strength of the research is deemed high as a result of strong internal and external validity, reliability and objectivity (Emden & Sandelowski, 1998). Such measures cannot be applied directly to qualitative research since the underlying assumptions differ significantly from

quantitative approaches. Lincoln and Guba (as cited in Emden and Sandelowski, 1998) indicate that the four pillars of quantitative work (internal validity, external validity, reliability and objectivity) have their corresponding pillars as credibility, dependability, transferability and confirmability in qualitative research. These four pillars are often referred to as the “goodness” of the research (Emden & Sandelowski, 1998). Others refer to trustworthiness. One of Emden and Sandelowski’s (1998) key observations is that the goodness of the research “is as much about where and how researchers derive their beliefs, assumptions, motivations and ways of working, as [it is] about judgement on research procedures and findings reached via the application of specific criteria” (p. 207). While quantitative measures are focused on the processes that ensure consistency within the research and the elimination of bias, qualitative techniques embrace the difference and variability within the research sample (Cohen et al., 2000; Creswell, 2003). As such, a phenomenological approach, the one to be applied in this research, required a closer examination of the assumptions, motivations, and experiences of the researcher. These were discussed my supervisor and noted.

Since there were no processes for measuring conventional quantitative reliability and validity it was important to design a qualitative research approach that would ensure consistency of the data across the sample and accuracy in reporting the experiences of the informants. Several key processes were in place to ensure the data were of good quality including field notes, journaling, peer review, member checking, and an audit trail. These processes are discussed within the contexts of Lincoln and Guba’s (1985) four pillars of qualitative work: credibility, dependability, transferability, and confirmability.

Credibility. According to Lincoln and Guba (1985), credibility is a measure of the confidence in the truth of the findings. There are processes that qualitative researchers use to ensure credibility; an example of this is member-checking. Member checking is a “set of procedures by which members [informants] can check the accuracy and adequacy of researchers’ synthesis of data” (Sandelowski, 1993, p. 4). To ensure that the informant’s experiences have been accurately reported, I provided a summary of the first interview for each informant. The summary was sent to the informant within 30 days of the interview. The informant was asked to confirm that the summary reflected his experience. Each informant had the opportunity to offer additional comments at that time or during the second interview.

Dependability. Dependability is showing the findings are consistent and repeatable. Peer review processes are examples of dependability. Peer review processes engage other members in the research to review the data and interpretation as well as to provide criticism or validation of the conclusions. My supervisor and I engaged in a peer review process to discuss my data analysis and interpretation. As indicated by Mayan (2009), having another research colleague to ask questions and provide criticism and support for the analysis of the data helps to ensure goodness in the research. Thesis committee members may also have been asked to assist in this process, although it did not occur.

Transferability. Guba and Lincoln (1985) indicate that transferability is showing that the findings have applicability in other contexts. Transferability can be achieved through the description of phenomenon in such detail that the researcher can begin to evaluate the conclusions that are drawn to consider how well they will transfer to other

times, settings, and cultures (Guba & Lincoln, 1985). Transferability can only be confirmed after the research has been completed. In this research some transferability occurred by comparing these results to those in the extant literature. Further transferability will be determined when the results are disseminated.

Confirmability. Confirmability is the extent to which the research findings are shaped by the informants (Lincoln & Guba, 1985). I used an audit trail, field notes, and a personal journal to capture additional thoughts and impressions of the entire qualitative process, ensuring detail that would not have been gained from transcription alone. An audit trail is an example of an approach used to ensure dependability that will be used in this research. An audit trail in qualitative research is a record of the decisions that were made during the research process along with the reasoning as to why those decisions were made (Mayan, 2009). According to Mayan (2009), this is an important element in qualitative inquiry as it enables the researcher to document and recall his/her decisions. “The researcher might have a difficult time building on or defending the analysis if major analytical decisions cannot be supported or recounted” says Mayan (2009, p. 112) with respect to the importance of the audit trail for the assurance of rigor. I captured the audit trail on my personal computer in the field notes.

Field notes were used “to construct a field text, providing important context and source of insight for the narrative data collected through interviews” (Cohen et al., 2000, p. 64). Field notes are the researcher’s personal notes that are written down during the course of the interview to provide the context for the auditory and written transcription. These notes help the researcher remember the informant’s body language, tone of voice and demeanour. Cohen et al. (2000) indicate that field notes should be written down as

soon as possible following a period of observation. I recorded my field notes during the course of the interview and expanded upon them immediately following its conclusion. That same day, I transcribed my field notes to provide optimal context for the interview.

A personal journal is “a record of the researcher’s assumptions, perspectives on how the research is unfolding, frustrations, challenges and highlights” (Mayan, 2009, p. 111). This journal is a source of data, but it is specifically for the researcher (Mayan, 2009). While field notes are the cues and observations from a specific interview, a journal is a continuous source of insight into the entire research process. I did not write in a journal throughout this research; however, I did track inflections such as laughing during the interviews directly in the typed transcripts. These provide additional context to assist with understanding of the tone of the interview or a particular comment..

While not accepted by the entire qualitative research community, these terms are generally considered to be accurate representations of the goodness of qualitative research. As Emden and Sandelowski (1998) indicate, qualitative inquiry remains an emerging field and as such, the quality of this research will continue to be examined and discussed. For this thesis, the aforementioned processes and techniques were used to ensure the best possible outcomes in terms of quality, goodness and rigor.

Ethical Issues

All research must concern itself with the ethical concerns and potential risk to the informants. By highlighting the potential risks to the informants in advance, the research maintains its transparency and helps to build trust. Based on the Tri-Council Guidelines for Social Science and Health Science Research in Canada (Canadian Institutes of Health Research [CIHR], 1998) and the requirements of the CDHA Guidelines (2010a), ethical

concerns were considered in eight areas: informant commitment, potential benefits, potential risks, informed consent, data management, security, financial compensation and conflict of interest. In addition, I considered the trustworthiness of the research as an important ethical issue.

Informant time commitment. The total time commitment for each informant was approximately 3 hours and 30 minutes. This consisted of the first interview that was approximately 60 minutes in length, and the second interview that was approximately 30 minutes in length. The final two hours were allotted for informants to arrange meetings with me, the researcher, review the consent forms, and read and comment upon the summary of the first and second interviews. The process, for each informant was completed within 5-6 weeks.

Potential benefits. Although there was not direct benefit to the informants, by engaging in a discussion that was focused on their insights and concerns into their arthritis care, informants may have gained a deeper understanding of themselves in relation to living with their disease and, therefore, personally benefitted from the research process.

This research may potentially provide benefits to rheumatologists by increasing their understanding of their patients. Similarly, health promoters may benefit by gaining information to make improvements to current programming. The Arthritis Society may also benefit from the results as the research can be used to further client care and programming. Finally, this research should add to the body of evidence-based research about AS.

Informant risks. There was a potential risk that informants may have become upset during the discussion (e.g. crying, communicating their emotions of anger or fear, or being visibly shaken) as some of the questions may have recalled upsetting memories or bring to light the longevity of the disease. Also the area of sexuality and sexual relationships may have been uncomfortable for the informant. As this study was voluntary, informants had the right to refuse to answer certain questions or retract comments after they were made. If informants did not want to continue the interview, the interview would have ended. None of these potential issues occurred. If an informant appeared emotionally upset at the end of an interview, I would not have left him alone. They were encouraged to take breaks if the discussion became too difficult. I would have also provided informants with a list of resources (eg. Mental Health Mobile Crisis Team) they might wish to contact after the interview, but this did not occur.

Informed consent. There were three stages of informed consent in this study. The process began when the potential informant had his first contact with me; he indicated that he wished to participate in the study. The second stage of consent occurred one week prior to the interview when potential informants received their reminder phone call. Finally, the third stage of consent was on the day of the first interview (see Consent Form Appendix E).

During the first stage, potential informants who had contacted me to express interest in the study were verbally given an overview of the project including potential risks and benefits as well as the time commitment that was required. Similarly, I reviewed the nature of confidentiality throughout the process with potential informants. I confirmed whether the potential informant met the inclusion criteria. If he agreed to

participate, an interview time was arranged and I mailed or emailed him a copy of the interview guide and a consent form. I also explained that written consent would be sought during the face-to-face interview.

The second stage of informed consent took place one week prior to the interview. Potential informants received a reminder phone call, text, or email from me confirming the date, time and location of the interview. The potential informant was given an opportunity to retract his participation in the research. If he wished to continue his involvement, he was given a chance to ask questions about the research process, specifically his confidentiality and the informed consent process. None of the informants expressed any concerns about the research process at this point of the interviews.

The third stage of informed consent occurred during the face-to-face interview. Informants were asked to bring their signed consent form to the interview at which point I verbally reviewed the form to ensure they understood key points such as the time commitment and confidentiality. If potential informants did not wish to sign the consent form, the interview did not take place. The informant's signature on the consent form acknowledged that he had read and understood the extent of his participation and his opportunity to withdraw from the research at any point without consequences.

Data management and security. For confidentiality and security reasons, pseudonyms were used for all informant names during the transcription process and for any reading by my supervisor. Pseudonyms were also used for any other identifying information such as rheumatologist's names. Additionally, workplace names were removed. All written reports and future results dissemination will use pseudonyms instead of informant names. Only I had access to demographic information such as

mailing addresses, email addresses, and phone numbers for the purpose of contacting the informants. This information will be destroyed once the project is complete.

Electronic data such as transcribed interviews were secured by password on my personal computer. Other data such as tape recordings and paper copies of transcriptions were locked in my supervisor's filing cabinet in her office at Stairs House, Dalhousie University. The data will remain there for a period of no less than 7 years for security and confidentiality reasons following CDHA's research requirements (CDHA, 2010a). After seven years, all data will be destroyed.

I used one transcriptionist, in addition to my own transcription, she signed a confidentiality form to ensure the informants names and personal identifiers were kept private.

Financial compensation. An honorarium of \$15.00 was given to each informant as compensation for his time and any costs he may have incurred for the research such as travel. The honorarium was not intended as an incentive to participate. In accordance with CDHA common practice, the honorarium was given at the end of the interview along with a receipt (Appendix F).

Conflict of interest. There was no financial conflict of interest in this study. There was potential for conflict of interest since I was a husband, nephew, and brother to family members living with spinal arthritis. As such, I may have had preconceptions regarding the results. As part of the research process I identified these preconceptions and assumptions with my supervisor and paid attention to them during the interview, the interview summaries and data analysis. I was transparent in my assumptions and met regularly with my supervisor and committee members to seek advice and guidance.

Another conflict of interest may have existed if I had had a personal relationship with an informant; however, this did not occur.

Summary

In this chapter the rationale was provided for using qualitative methods, for the use of a phenomenological approach and how the 12 steps of The Vancouver School were implemented. The final two sections included a discussion of the trustworthiness of the research and how the ethical guidelines consistent with both Dalhousie and Capital District Health Authority were met. The next chapter discusses the key themes found in the data.

Chapter 4: Findings

The intention of this research was to explore the lived experiences of young men with AS within the context of work, personal life, and the barriers to accessing care from the medical community. This chapter describes the informants and identifies the themes that arose from the interviews.

Each informant either selected or was assigned a pseudonym. Given this is a lived experience research project, using names rather than informant numbers when providing specific quotes, contributed to humanizing the research. All of the quotes have been taken verbatim from the transcripts. In order to provide the essence of the quote rather than being distracted by various verbal idiosyncrasies, vocal fillers such as “um”, “ah” have been excluded. If pauses or other non-verbal indicators added to the meaning of the quotations they were included. To protect the confidentiality of the informants and to ensure that they were not concerned about how they spoke to me as the researcher, descriptors such as place of work and other identifying pieces of information were omitted. In keeping with qualitative methodology (Creswell, 2003), rather than reporting number of respondents for each theme, the following designations were used: “Most” means six of the seven informants, “Some” means four or five of the informants, and “Few” means two or three of the informants.

Participant Demographics

The 13 interviews (7 first interviews and 6 follow up interviews) took place over a period of 14 months. At the time of the first interview, the informants, all Caucasian men, ranged in age from 23 - 37 years old with a mean age of 31.3 years. Informants had been diagnosed with AS when they were between the ages of 12 and 30 years old. All of the

informants had been diagnosed with AS by a rheumatologist for more than one year and, as a group, had been living with the disease for an average of 8.4 years. Each informant was living in the Halifax Regional Municipality (HRM) of Nova Scotia at the time of the interview. Most informants lived in urban HRM while one lived in suburban HRM. Therefore, all informants met the inclusion criteria.

Most of the men who were interviewed had full-time employment while the final man was on long-term disability as a result of his AS. None of the informants were currently married although two were divorced and six were in long-term relationships with a woman. All of the informants identified as heterosexual men. One of the informants had children and each of these children was born after symptom onset.

To provide some context for the subsequent presentation of themes with their accompanying quotations, the section below provides a table (p. 76) describing some general demographics as well as a more detailed biography for each informant. Age ranges, rather than specific ages, are used and workplace designations, names of rheumatologists, as well as other identifiers have been changed to protect anonymity.

Tom

Tom is 30-35 years old and first experienced symptoms of his AS when he was 22. Tom lives in urban HRM, he is not married but is in a long-term relationship with his girlfriend who does not live with him. He is employed part-time in a non-labour setting for an organization and is self-employed part-time, also in a non-labour setting. He is a self-described “private” person who does not openly discuss his disease. He has long-term damage to his neck as a result of his AS. Tom has been diagnosed for more than 10 years.

Table 1: Informant Characteristics

Informant	Age range	# of Years Living with AS	Employment Status	Relationship Status	Marital Status
Tom	30-35	>10 years	Employed full-time	Long-term with girlfriend, no children	Never married
Jim	20-25	>10 years	Employed full-time	Long-term with girlfriend, no children	Never married
Rick	20-25	5-10 years	Employed full-time	Not in a relationship, no children	Never married
Tim	30-35	>10 years	Employed full-time	New relationship with girlfriend, no children	Never married
Josh	35-39	>10 years	Employed full-time	Long term with girlfriend, three children	Divorced
John	30-35	5-10 years	Employed full-time	Long term with girlfriend, no children	Never married
Les	30-35	>10 years	Unemployed	Long term with girlfriend, no children	Never married

Jim

Jim is 20-25 years old and first experienced symptoms of AS when he was a teenager. He lives in urban HRM and is not married but is in a long-term relationship

with his girlfriend who does not live with him. Jim is employed in a trade that requires some physical labour. He is physically fit and is surrounded by close friends. Jim has been diagnosed for more than 10 years. He has no long-term visible damage from his AS.

Rick

Rick is 20-25 years old and first experienced symptoms of AS when he was a teenager. He lives in urban HRM and is not married and did not have a girlfriend during the time of the interview although he did indicate that he was heterosexual. Rick is employed in a position that requires some level of physical labour. He has been diagnosed with AS for 5-10 years. He is a self-described open person who has struggled in the past with drug addiction. He has no long-term visible damage from his AS.

Tim

Tim is 30-35 years old. He lives in urban HRM and is not married but does have a girlfriend who does not live with him. Tim is employed part-time in a management position and is self-employed part-time. Neither position requires physical labour. He has been diagnosed with AS for more than 10 years. He is a self-described “private” person who has strong opinions about his health care. He has no long-term visible damage from his AS.

Josh

Josh is 35-39 years old and first experienced symptoms before he moved to Nova Scotia. He lives in suburban HRM and is divorced but is currently living with his girlfriend. Josh is employed full-time in a position that requires some physical labour. He has been diagnosed with AS for more than 10 years. He is open about discussing his AS and is very strong willed about the management of his disease. He has no long-term

visible damage from his AS.

John

John is 30-35 years old and first experienced symptoms in his teenage years. He lives in urban HRM and is divorced but is in a long-term relationship with his girlfriend who lives outside Nova Scotia. John is employed full-time in a non-labour setting. He has been diagnosed with AS for more than 5 years. He is a self-described “private” person and does not openly discuss his AS with co-workers. He has no long-term visible damage from his AS.

Les

Les is 30-35 years old and first experienced symptoms of AS in his early twenties after an accident. He lives in urban HRM with his mother and grandmother and is on long-term disability. He has been diagnosed with AS for more than 10 years. He is open about his illness and discusses it freely. He is not married but is in a long-term relationship with his girlfriend who does not live with him.

All of the informants were monitored regularly by either a rheumatologist or a family physician and had been prescribed various treatments including prescription medications and physiotherapy. While each of the men had been prescribed a medication not all of them chose to adhere to this treatment. The medication therapy that was used by each of the informants ranged from no therapy to Anti - TNF. See Table 2 (p. 78) below for a full description of the informant’s treatment for their AS.

Table 2: Medication Therapy the Informants are Using to Treat Their AS

Informant	No Therapy	Anti- Inflammatory	Disease Modifying	Narcotic	Anti-TNF
Tom					√
Jim		√			
Rick					√
Tim		√			
Josh	√				
John			√		
Les				√	

In summary, the informants for the study were young adult men who had been diagnosed with AS for an average of 8.4 years. All but one of the men was working, either full or part-time, only two of the men had been on long-term disability as a result of their AS. While most of the informants did not show any visible disability (one man did), all the informants indicated that during a flare-up (a period with more active inflammation), they would show more outward signs of their disease such as moving slowly and obvious changes in gait. Some chemotherapeutic regimen was part of the daily lives of the men. None of the men is currently married although some have long-term committed relationships.

Emerging Themes

As summarized below in Table 3 (p. 81) the overriding theme of *I'm a Man* emerged from the data. This theme included four key themes: 1) *Trying to maintain*

normalcy, 2) *Do what I like to do*, 3) *I have to Work*, and 4) *I don't really ask for support*.

Each of these key themes had several sub themes.

Overriding Theme: I'm a Man. The overriding theme to emerge was hegemonic masculinity. On the surface, this may seem to be obvious given that the informants are men, but despite their chronic illness, both overtly and covertly, each of the informants reflected Western cultural hegemonic masculine behaviours or attitudes. Most overtly, the informants referred to being men:

Because I'm a man and I want to feel like a man. I don't want to be a pussy. You know, I wanna try to do the stuff that I want to do, right? . . . the symptoms is what I was really trying to hide when I first got diagnosed because I felt like such a non-man, you know, I felt like a girl or something . . . I can't go with the same type of intensity . . . Even if I could still do stuff it still doesn't seem good for me because I could get hurt. But I still try to do them sometimes, obviously. (Les).

More covertly, the informants referred to work and its importance in their lives, the role of work being a critical part of Western hegemonic norms: *I feel like I'm . . . broken or something . . . Otherwise I'd still be working right? (Les)*. These norms permeated the interviews and also manifested themselves in several behaviours including an avoidance of health care, placing high importance on work, engaging in physical activity and shaping their physical bodies.

Masculinity was embedded in each of the decisions and experiences of these men. The key themes emerging from the data highlight these masculine norms and provide a depth to the desire to be normal, be in control of their lives, participate at work, and to be open to support.

Table 3 – Themes of the Research

Overriding Theme	<i>I'm a Man</i>			
Key Themes	<i><u>Trying to maintain normalcy</u></i>	<i><u>Do what I like to do</u></i>	<i><u>I have to work</u></i>	<i><u>I don't really ask for support</u></i>
Sub-Themes	<i>I get really fed up with it</i>	<i>Sitting around's not doin' nothing</i>	<i>I try to grin and bear it</i>	<i>You learn about your car when things go wrong</i>
	<i>I'm not looking for sympathy</i>	<i>This is not gonna impact me</i>	<i>I gotta work, right?</i>	<i>The support will be there</i>
	<i>I thought it was going to go away</i>	<i>Since I got on the medication. . .</i>		
	<i>Everything looks good</i>	<i>There may be a ticking time bomb</i>		

Theme one: Trying to maintain normalcy. A strong desire to live a normal life with their AS was apparent in some aspects of the informant's lives: however, it was more challenging in others. Feeling and acting normal consisted of performing key activities and social roles that were consistent with other men who do not have AS. These included maintaining long-term relationships with their girlfriends and establishing themselves in a career path of their choosing. Despite being able to carry through with these other aspects of their lives, they were complicated by their disease and resulted in making decisions about **how** to feel normal. A typical example of this challenge is expressed in the quote below.

Somehow, trying to maintain normalcy in your life and not, not bow down to 'I gotta terrible disease and I'm gonna die'. (Tim)

Strategies to achieve normalcy were implemented in several different ways in keeping with Western masculine behaviour: making decisions (particularly around

medication use) disclosing or not disclosing health information to family, friends and colleagues, avoiding of health care, and handling interactions with health care providers. One clear way to feel normal was to make decisions about when or if to take medications despite medical recommendations to do so.

Sub-theme 1: I get really fed up with it. The informants discussed the decisions they made and how the decisions affected their day-to-day lives. In some cases, the choices resulted in negative effects to their health but making the choices was important to ensuring their sense of normalcy. This decisional balance as discussed by Geller, Mendoza, Timbobolan, Montjoy, and Nigg (2012) “is a measure of attitude that captures how individuals weigh the consequences of a specific behaviour in terms of pros and cons” (p. 242). Decisional balance played a key role in determining which choices the men made in their day-to-day lives. In particular, informants discussed how their medications were a barrier to them feeling normal; therefore, they decided to alter the recommended regimen.

Ok. It's my birthday tomorrow [Friday] and I'm flying to Ottawa tonight. Probably going to be drinking a lot . . . so I didn't take my drugs yesterday [Wednesday] . . . I'll wait 'til Monday . . . I probably should have taken them on Wednesday in the cycle . . . I had a bunch of work to do. I got a big report that's due tomorrow, I gotta leave tonight for Ottawa. If I had taken my drugs yesterday, today would have been more of a write off, and I didn't want to worry about drinking. There, that's the decision. (John)

While these occasional interruptions in medication use were most common, to feel more normal others made decisions to stop taking their medications for a period of time or avoided medications altogether.

[The rheumatologist] put me on the [medication] and at times I would . . . you know start to believe, you know, maybe I don't need it. And I would start self-weaning. And forget to take it at times . . . I don't want to take this forever . . . I gotta get off it. (Josh)

The informants who chose to feel normal by stopping their medications for a period of time described how they would rationalize their decision.

I get really fed up with it and I just say I can't do it. And maybe I'll convince myself that I'm feeling really good [and that] I don't need it. (John)

Although forgoing or changing medication routines sometimes resulted in negative effects to their health, informants rationalized these negative consequences by explaining the decisions were not necessarily the result of the disease but what might occur to anyone under the circumstances (i.e. someone who is normal).

I know if I'm in bad pain, it's my fault usually. I, you know, did something I shouldn't have done the night before or I was up until 5 in the morning and I ended up, you know, I didn't take my medication and I feel asleep on a chair or something then I know half the next day is going to be more uncomfortable than it should be. (Tim)

This rationalization of choices extended to the informants' understanding of their disease and the learning that they have, or have not, done in this area.

And I don't always take the correct choices but I think I've got a feel for what my body's doing and how to keep things in check. There's not a lot of hope where I feel if I dive right into this strict [medication and physical activity] regimen that I'm going to be a hundred percent. I've come to the conclusion that . . . I'm never going to be a hundred percent. This is what I've got and I've got to live with it the best that I can. (John)

Decisional balance concepts are evident in the choices the informants made to feel normal with respect to their medication use, but they also made decisions about discussing and disclosing their AS in other parts of their lives. These differing social roles resulted in different outcomes.

Being normal for the informants involved continued participation in their normal life activities. Davis et al. (2011) define social role participation as “involvement in life situations” indicating that “such life situations or roles are broad patterns of purposeful

behaviour at the level of societal involvement” (p. 1765). Social roles “include involvement in close relationships (e.g, parenting), being a student or employee, being a patient, and aspects of a person’s identity related to social and leisure activities (e.g, volunteer) (Davis et al., 2011, p. 1765).

Sub-theme 2: I’m not looking for sympathy. Being normal meant hiding their AS from work colleagues and minimizing it with their family members, friends and relationship partners. Western masculine norms suggest that men are quiet about their health concerns, preferring to being perceived by their colleagues or family members as strong and capable. Those who did not disclose their disease generally at work were self-described “private” people who wanted to avoid pity from their colleagues because they believed they could contribute as well as anyone else.

I really don’t tell people at work because . . . I guess I consider it a downfall . . . you know something to my disadvantage more of like a weakness and I definitely don’t want, I’m not looking for sympathy from anybody at work and I feel like if I talked to somebody at work about it that they would kind of take it that way. (Jim)

Conversely when workplace colleagues were considered close, more like normal family members, there was a greater openness to disclosing

I probably have maybe seven or eight good close friends and my work staff, you know, and they’ve seen me coming to work with a knee [that was heavily inflamed and swollen] like, I’d wear shorts at work and my knees like that and the next two or three days like I’m walking normal, so it’s just . . . like I said, they’re like a family, everyone is really good in there, they all have a pretty good idea of what I go through. (Rick)

This idea of family and family closeness was evident because, all the informants reported they had disclosed to family members. Nevertheless, despite the unanimous disclosure to family members, the degree to which disclosure occurred depended upon the closeness of the relationship.

Most of the informants placed a higher value on discussing/disclosing their AS with friends and girlfriends than with family members. As the informants were closer to some of their friends, they felt more open to discuss their disease. Nevertheless, as an important aspect of feeling normal, even with close family and friends they did not want sympathy.

It really depends on how close with the person I am. If it's a person that I really like feel close to or talk to a lot it would probably come up in conversations just because it is a little tidbit about me. But for the most part like I don't really complain about the pain so much that a friend would notice and consciously ask you know what's wrong? And even when that comes up I would I always say you know I just I have arthritis, I've had it for years. I never really tell them that I have AS at all. (Jim)

The most significant disclosure occurred with the most intimate partner

When it comes to my girlfriend I would say that she probably sees it more than anybody that I'm around because she's the you know she's always the one with me late at night or whatever and sometimes when I'm you know rolling around for hours in bed trying to get comfortable. Yeah it's definitely her that sees it the most now that I think about it. (Jim)

The one man who allowed others to see the extent of his AS revealed how he had lost friendships: “Cause they know that I can't do the stuff anymore so they just don't bother with me” (Les).

As well as this involvement in social roles both at work and in intimate relationships, the desire to be seen as normal carried into relationships with the medical care system and health care providers. In these arenas, the informants demonstrated behaviours consistent with western masculine norms, beginning with their diagnosis and continuing through to the day of the interview.

Sub-theme 3: I thought it was going to go away. A consistent sub-theme for most of the men was that they avoided health care unless it became essential. Prior to

diagnosis, most hoped that their symptoms would go away. In its most extreme form, avoidance occurred for several years and was expressed through a variety of behaviours including delaying access to care and ongoing treatment.

[although I was diagnosed before I started college] *I didn't start, uh, seeking help about it until I finished college. Then immediately it was like ok. I need to sort this out because this isn't going away. I thought it was going to go away and it wasn't.* (Tom)

This attitude resulted in a delay in the diagnosis of Tom's AS which potentially caused a worsening of his condition and led to long-term damage to his spine.

Later in the process, after having been diagnosed with AS and despite recommendations from their rheumatologists, most men continued to avoid the health care system as much as possible. This was demonstrated through a reluctance to participate in additional therapy and support groups of any kind and a reluctance to adhere to the prescribed medication regimen. This antipathy to regular medical attention extended beyond physicians to avoidance of allied health professionals such as physiotherapists, key members of the health care team in managing AS.

I always kind of shrugged it off and you know did, did the exercises every now and again, but just didn't have the right attitude towards if it was going to help me . . . When your hips are sore like that and your knees are sore like that I didn't feel like the physio was going to help it. (Rick)

There was a specific view that a delay in seeking care made no significant difference to the progression of their disease.

So I don't see how any of the doctors would have put two and two together on those minor pains . . . So, I can't see that me pushing a little bit more would have gotten anywhere. 'Cos these were very short, sort of, one week maximum type of things that went away. So, when things go away, you don't keep going to the doctor. Right, you get better and you try to take note of maybe what might have helped or didn't help but you don't tend to keep on pursuing things if it's once every couple years, right? (John)

This avoidance of health care is an expression of typical western hegemonic masculine norms. The need to feel normal resulted in a delay in care that, in some case, caused long-term physical damage. While avoidance of health care generally, emerged from the data these men required some medical assistance. Given that they were recruited from the Rheumatologist database, it was clear that they had experience with some regular medical care. When discussing their medical care, there was a distinct difference in the way those with severe AS thought about their rheumatologists than did those with less severe forms of AS.

Sub-theme 4: Everything looks good. Informants sought to maintain their sense of normalcy with their health care provider most commonly through regular check-ups and affirmation from their health care providers that they had a recognized disease.

Informants with more overt symptoms and signs of AS (i.e.: neck damage, spinal fusions, and severe mobility challenges), expressed general satisfaction with the way they were treated by their specialists. They expressed their confidence in the physicians from whom they received care.

when I finally seen somebody that knew what they were doing, a rheumatologist . . . he just put me down on this table and started stretching me. But he did different stuff from the other doctors that checked me . . . The examination seemed more thorough and stuff. (Les)

Conversely, those with less severe AS reported they were not getting their needs met from their current health care providers. This group experienced conflict about needing to be seen as normal to the outside world while needing to be validated by their rheumatologists that they had a legitimate condition. When this validation did not occur, informants said they felt they were dismissed as legitimate or “real” AS patients.

You only go once a year for half an hour or less so . . . it doesn't feel like you have a condition. You basically have a bottle of pills and they're anti-inflammatories, you decide how often you're going to take them, and you see somebody who tells you to touch your toes once a year, and, you know, you've got a certain amount of expansion between your vertebrae, blah blah, and everything looks good (said with some sarcasm). (Tim)

Informants felt that this cursory treatment of their condition challenged their sense of having a real illness. This is consistent with the literature review that was conducted for this research, indicating that men “need a means of legitimizing their visit to a doctor to keep their male identity intact” (Galdas et al., 2007, p. 223). The informants were seeking legitimacy or validation from their physician as an outcome of their medical appointment. In this instance they desire to be “normal patients” not frivolous ones.

In summary, the informants desire to maintain their sense of normalcy through a continued participation in social roles was evident. These social roles were broad and encompassed the interactions in their personal and professional lives. While wanting to be “normal” in most situations there is a time, in medical appointments, when those with less severe AS want to be acknowledged as having a legitimate illness.

Closely linked to the need to maintain normalcy is the desire to stay in control. Being in control is a common element of western masculinity. So, although these men had various health issues related to their AS, they sought to retain as much control in their lives as possible.

Theme two: Do what I like to do. All of the informants elected to exert some control of their disease through physical activity, disease management philosophies, and medications. Additionally, they expressed concerns about the lack of control they perceived themselves to have on issues surrounding their futures as fathers both genetically and in terms of their disease progression.

Sub-theme 1: Sitting around's not doin' nothing. All of the men placed a strong importance on physical activity and maintaining their physical bodies as a means of exerting control over their lives. Physical activity was consistently used to minimize discomfort or pain associated with their AS. As well, a few informants used healthy eating in conjunction with physical activity to control their pain levels and improve sleep.

If you're exercising all the time and doing work for your core and things like that then I generally don't have any pain through the night or anything like that and in the morning I'm not really stiff so, it just means that, yeah, you become very much conscious of what you're doing and what you're not doing I guess. (Tim)

Despite some restriction on engaging in certain physical activities due to pain levels, these informants used physical activity to maintain independence and control over their disease.

Some days I actually went from crutches to bike, bike to crutches, you know? . . . yeah, sometimes I was in so much pain that I thought, Jesus, I gotta do something cause I'm laying there for weeks and I just get sick of it. So I said screw it, I'm gonna bike . . . sitting around's not doin' nothing, maybe physical activity will do something! . . . The pain would still hurt and stuff, but I'd feel a little relief from just getting out. (Les)

Physical activity and healthy bodies were also part of a larger disease management approach to living with AS.

Sub-theme 2: This is not gonna impact me. All of the men were experienced at managing both their disease and their lives. While physical activity and effective medications were the most common approaches to disease management, a secondary approach was employed through utilizing positive mental and emotional health strategies.

Physical activity not only provided some control over an unpredictable condition, in combination with medications, it also allowed some creativity in managing the disease. Some men expressed their independence by creating a strict regimen consisting of

activities recommended by their health care team in combination with those that they deemed helpful over time as a result of personal experimentation.

Yup, oh yeah, now I'm pretty active. Well things changed at a certain point there, when I eventually got like approved access to Remicade . . . Yeah, I exercise now though, I like jog and, do stretches, I've just found my own version of stretching I've found out what's kind of worked over the years . . . figured out this worked this that doesn't work, try this made up some things on my own that I've found helped. (Tom)

As with other chronic conditions, the informants believed that psychological strategies as well as physical strategies were important to living with AS.

I'm a firm believer in my positive attitude makes it better. I think emotionally, mentally if you say, I'm gonna, this is not gonna impact me, then it won't. And maybe, maybe that's all hoopla, I don't know. But, that's what happened to me so that's what I'm going with. (Josh)

Another informant believed in achieving a balance of physical activities, medication, and positive thinking as a means to manage his disease.

It's not really an option for me not to exercise . . . I try to go to the gym, you know, or do something active six days a week which I do. Right now I'm on [a drug] which is a dinosaur of a drug I guess and quite hard on your stomach I think but I've been on it for a long time and I don't have any real problems with it but it works well for me . . . You can take the medication and live the lifestyle that you are living or you can not take the medication and do x, y, and z. Yoga, Tai, and that type of thing. Whatever, it substitutes for the medication . . . Positive thinking leads to positive behaviour which is a good thing. (Tim)

While all of the men seemed to accept their disease to a greater or lesser extent and each has developed his own method of management, one of the informants described how having a chronic condition shifted his life perspective.

I think what [AS] does is shift your priorities, so, maybe you're mid-20 and you have this ideal view of your life . . . And then something like this comes along . . . I went through some rough times and, basically I probably engaged in some things that maybe I wouldn't have before. I don't think as long term as I used to, so . . . I ended up cheating on my wife . . . And I probably just did what felt good at the time . . . and didn't really care. (John)

Managing AS through physical and psychological strategies is almost always accompanied by the use of medications. The informant's relationship to their medications is complex while medications play a role in disrupting a sense of normalcy, they also offer an opportunity for controlling both their disease and their lives.

Sub-theme 3: Since I got on the medication . . . Informants showed significant variance in their thoughts and opinions on medications and adherence to them. Some of the men found that medications were extremely helpful in the management of their disease, while others thought them to be dangerous and costly. Adherence appeared dependent on a combination of physical and psychological effects of the medications. Those who found the medications helpful attributed much of the success in their lives to these medications including returning to the workforce and improved health outcomes.

Since I got on the [medication], . . . I just felt so good, and . . . I've been slowly losing weight and now I've quit smoking and I just feel like a million bucks these days. (Rick)

While some of the informants found the medications to be helpful, there were also men who indicated a lack of trust in the medications, particularly when the medications made them feel worse than not taking them, interfering with their daily lives.

Right now I'm on [a medication] . . . so that wipes me out for pretty much one day a week. And, it's great if I'm in the city and I'm just having a normal week so I can take it on a Sunday and kind of write off my Sunday . . . sometimes will have to give a presentation on a Sunday so I have a rough time with that and I do cheat on the drugs. I'll just put it off for a couple days, a week maybe, and I get in trouble with that and that's when I flare up. (John)

These informants chose not to adhere to the medication plan as a way of staying in control of some aspect of their lives. For others, the regular use of medications reminded them that they were ill, to test this, they would deliberately stop the medications.

sometimes I'll, I'll just say, I've had enough. I'll take a month or two off or something. (John)

As well, some informants expressed concern about medication side effects, and overall effectiveness.

I don't agree with [my medication] in general . . . it's pretty much killing me. It's killing me. It's killing my liver. (John)

A few of the informants indicated cost was a barrier to using medications. These informants mentioned how the medications are quite expensive and given that they are a monthly or semi-monthly cost, they couldn't justify their continued use or could only afford them through compassionate access.

The anti-inflammatories cost like a hundred bucks almost. And I get like 700 dollars a month . . . and they don't work. So, why am I going to pay \$80 for pills that don't even work? . . . And my other pills cost like \$30 and when I take them, they work. Take one of those the pain goes, or at least decreases by fifty percent. (Les)

Through the use of physical activity, positive thinking and the use of medications, the informants exercised some control over their disease and its outcomes. However, they expressed concerns about a lack of control over the potential for the disease to affect future family decisions.

Sub-theme 4: There may be a ticking time bomb. Each of the men were asked about the relationship of genetics to their disease and whether they knew of any family history of AS. While most of the men did not report a family history of AS, a few of them did; albeit not always medically accurately.

Well my grandfather was diagnosed with it before I was but my uncle was diagnosed with it after I was. And uh, I think it was my Mom talking to him that said, you know, if you have the same type of pain as him maybe you should go mention this to your doctor. And I think he did and they said yeah you've definitely got that. (Jim)

Despite showing no family history of AS, a few of the informants were concerned about their children inheriting their disease.

I'm concerned for my children. Both parents now have auto-immune. You know, I'm diagnosed with AS, she's diagnosed with [another auto-immune disease]. So, what will that combination mean for the three of these guys . . . there may be ticking time bombs going on with their bodies. (Josh)

While there was some concern from a few of the informants about their children inheriting AS, other men reported more concern about their ability to interact with their children and participate in activities with them as both they and their children grew older.

But if I was thinking about anything it probably wouldn't be the genetic issue. It would probably be like oh, like when my kid's like ten and I can't coach his hockey team maybe, or I can't do the things that I would like to do. That probably enters my mind a bit more. (John)

While most of the informants did not indicate that cost was a barrier to their decisions around family planning, the one man who had the most severe AS raised the possibility of having only a disability pension as a future concern; the cost of treating his illness would affect his ability to care for a child.

I'm kinda scared to do that at this point because even though if I had a kid it would be great, I'd love the kid and whatever, but financially it scares me [in terms of paying for all of the expenses of a child while on long-term disability]. (Les)

In summary, the informants displayed a strong desire to be in control of certain aspects of their lives. Topics such as physical activity, managing their disease and medications as well as whether or not to have children and AS impact on them have been noted as very important to the informants. Similarly, the role work played in the lives of these men, particularly in seeing themselves as providers was also of high importance.

Theme three – I have to work. All of the informants placed a high importance on their work. Most of the informants were employed full-time (two of whom were

employed part-time with an organization and self-employed) and one was on long-term disability. Despite the differences in their participation at work, it was important to each of them. Since the full transcripts are not revealed in this thesis, it should be noted that each of the men described much of their life in the context of their work. Most of the timelines and references to dates are in relation to which job they were working at the time.

No, I was still on meds then... and think I stopped taking meds when I was at [workplace 1]. Yep, and it was not until I started at [workplace 2] that [my rheumatologist] dismissed me as a patient. (Josh)

Sub-theme 1: I try to grin and bear it. Most of the informants placed a strong importance on work and the ability to work. Most of the informants were able to work full-time; however a few had to make adjustments to their work life including transitioning to part-time work or going on long-term disability. Despite the variances in the level of participation at work, informants identified strongly as needing to contribute to the workforce and to provide for themselves and those around them.

Most of the informants indicated that they valued their ability to provide for themselves and those around them financially. However, Les was unable to work and expressed his concern about being to provide for himself, his child and his girlfriend if they had a child together, *“she wants babies and I’d like to have babies too but I can’t support them off the money I have right now.”*

Most of the informants had established their career path and had been supporting themselves independently for several years. However, a few of the informants indicated they were still seeking their career path or had recently begun in a “career” position. These informants discussed their desire to tolerate the pain associated with AS in an

effort to be seen as reliable employees.

I would be lying if I said I never you know called in sick because of the pain...I definitely have... at a few different jobs even before this one... I've been working at this job for about two years but it's . . . my first serious career job so I try to you know to grin and bear it and go to work anyway. (Jim)

Long-term disability was shown to have serious effects on the informants' ability to feel normal and in control of their lives. Returning to work, even part time work, was shown to be of great importance.

He let me come and work, you know, ten till four. Come when you can, we'll always have stuff for you to do. It wasn't a set hour. By . . . June, then I was working forty hours a week. Monday to Friday kind of thing . . . [My rheumatologist] was amazed that I was doing that and that I would come in dusty after working all day and . . . he's like, how are you doing that? Because he had saw me when I was on my death march. (Josh)

While most of the informants were able to participate in work at some level, one of the informants clearly defined his struggle with being on long-term disability and the desire to be able to work to support himself. Work is a vital component of the identity of these men. When faced with the inability to perform certain aspects of work, it challenges this innate sense of masculinity.

Sub-theme 2: I gotta work, right? All of the informants indicated that their AS posed occasional pain and discomfort that would affect normal work activities. For some AS posed challenges to participating at work such that they were forced to go on disability or change their position by moving to multiple part-time jobs. These changes proved stressful.

Then I had like a supervising job for a while. And I had to quit it . . . that [the job] was definitely bad for my health . . . I felt like I had to work more hours than anyone I was supervising if I was going to be the supervisor right? If I was asking them for them to do a lot of hours . . . that I'd be a hypocrite if I didn't do even more hours than them. So I'd do that and it was that many hours hunched over a computer. I'd try to try to think about my posture and stuff but after a while it was just impossible. (Tom)

A few informants had to balance self-employment and working for an organization so they could improve the management of their AS at work and minimize the negative effects. These informants discussed the benefits of self-employment on their health.

It's all just something I do, I'm not working for anyone else when I do it so I can and I can do it from home. So I can go and down, I can take breaks, I can stretch and that kind of thing whenever I feel like it. I don't worry about looking like a bad employee who's taking too many breaks (Tom).

Changing to part-time work at an organization or being self-employed part-time allowed for the proper balance in their work life and also decreased the impact of the disease on how they viewed themselves as providers.

While most of the informants were able to participate in full-time work, one informant was on long-term disability and he indicated that it was frustrating because he wanted to work. His inability to work caused him to feel like less of a man. Throughout the course of the two interviews he referenced his inability to work regularly and mentioned his desire to find something that he could do with his AS.

I don't know what's gonna happen but I got a plan, you know, I'm thinking maybe I can get my license or something. Then make money that way . . . Maybe I could deal with sitting in a car . . . nice comfortable seat or something . . . I'm gonna try to get my license and see what happens . . . cause I gotta work right? (Les)

In all instances, whether employed or not, the informants judged their progress and their success as men, through their ability to work.

In summary, work was shown to be of high importance for the informants in this research. Work was a critical component of their identity as young men and they placed a high value on their ability to provide for themselves and their families. Maintaining their ability to work full-time was ideal, but if that was not possible, then part-time work was a good, but less agreeable, alternative.

While all of the informants valued their ability to work and provide financially for themselves and noted the importance to them in fulfilling their male roles, part of managing their AS was also dependent upon the type and amount of support they received to manage their illness.

Theme four: I don't really ask for support. Getting and maintaining support was an important part for these men in managing their disease and their lives; however, there were differences in informants' acceptance of the different levels of support: informational and emotional. According to Eriksson and Lauri (2008), informational support is described as "giving information about medical and nursing care as well as organizational information" (p. 9). Emotional support "involves elements of supportive psychotherapy, which may range from dealing with issues actively to simply being close" (Eriksson & Lauri, p. 9). Some of the informants actively sought informational and emotional support, while others did not.

Sub-theme 1: You learn about your car when things go wrong. All of the informants indicated that at some point since their diagnosis, they had received information on AS. Most of the informants conducted their own research on the topic of AS. Some of the men determined that they did not want to learn any more about their AS, while others indicated that they were seeking information on an ongoing basis.

For those who did not seek out additional information on their AS, the material they received from their rheumatologist and family physician became their only source of information. The amount of this information however, became a source of anxiety for some. Rick shared his feelings about the information that was provided to him when first diagnosed, “*when they diagnosed me they gave me a pamphlet like that was so thick I was like pffft, that’s what I have? Crazy. . . I never really got into it, right.*” When asked if he has researched anything on his AS, Rick replies, “*Not so much.*” For others, reading material other than that provided by their medical practitioners contributed to depression and anxiety about their condition.

I haven’t really felt the need to do that much reading, that much research on it . . . The more I know the more depressed I get about it . . . So, maybe I should, maybe I should dive right into it, but I think I know the basics and I know what I should be doing and what I should not be doing. (John)

Most of the men indicated that they had an ongoing desire to learn more about their AS. They reported conducting regular, extensive research into their condition.

You know, sometimes like for a while you, you know, have something that feels like one of your kidneys is sore but it’s not really your kidneys, it’s kind of like the way your rib is joining your back or something like that so, you know, you do a little research on that or you go to the doctor or whatever, so it’s just, it’s like having a car. You learn about your car when things go wrong. (Tim)

Each of the informants determined the level of informational support they wanted. Furthermore, they accessed this information in a variety of ways including online, by book or from their health care provider.

Although the informants were able to control their intake of information, they were less able to control emotional support. Although they sometimes desired to do so.

Sub-theme 2: The support will be there. Handling a chronic condition, particularly one that is diagnosed in young adulthood requires not only medical support but also

emotional support. For these informants, emotional support varied based on the level of intimacy with friends and family. Young adulthood results in movement away from the nuclear family (parents and siblings) to establishing one's own primary relationships with partners, children, close friends, and colleagues. In this study, it was clear that these relationships and the emotional support received from these individuals played an important role in the informants' quality of life.

Family members influenced each of these men in different ways. "*The family support [from my parents] was right there from the beginning. They were very concerned*" (Josh). While both parents offered support, mothers in particular played a key role in promoting action toward health care especially with the informants who were diagnosed at a younger age although this support was not always welcomed.

I have an overly concerned mother . . . She was always trying to send me things about what it could possibly be before I was diagnosed. Sending all this stuff for me to read and . . . all her theories and her friend's theories that she would talk to . . . and then afterwards that kind of continued too . . . she would occasionally get the idea that maybe you don't have this, maybe you have this instead, you know. (Tom)

Consistent with Western norms, men spoke less intimately with their fathers. While the informants report a good relationship with their fathers, it did not usually extend to a discussion of their AS.

He doesn't really want to hear [me talk about my AS], like he's never said he doesn't want to hear it but, it almost seems like it doesn't really matter if I tell him or not. (Jim)

Some of the informants reported supportive parents, although others indicated that their parents kept their distance throughout their disease. This was more common in the men who were diagnosed at an older age. These men reported their parents had a low level of involvement in their care and that they were comfortable with this arrangement.

Well I think I was in communication with my parents and then sort of on a casual basis with symptoms and stuff that was happening but . . . as far as, from the day to day situation, it's, I have a pain in my back and I take this pill to address it... there was a considerable amount of, I suppose stress and concern . . . I think the support of the family will be there if it's required . . . it's just that I have a perfectly normal life I think. (Tim)

Some of the informants described how they did not need to discuss their AS with their family members because they did not feel like they needed any support. This is consistent with hegemonic masculine norms.

Well I think that they don't know anything about it really. There's not really any support. I mean, I carry all my suitcases and whatever! I help them move... I don't really ask for support and none specific to the condition is provided I would say. (Tim)

Some of the informants reported not discussing their AS in detail with their family members for a variety of reasons including the perceived value of their input.

I don't see [my parents] as much as I used to. There's not a lot they can do. They probably feel sorry for me more than anything, so maybe moral support. But, they're not doctors or science people, they don't have any brilliant ideas. (John)

The informants also discussed the supportive role that friends play in their life. All of the informants indicated that they valued their friendships, yet some of the men had strong relationships with a broad group of friends while others were much more solitary.

I don't surround myself with many people you know, I probably have maybe seven or eight good close friends and my work staff. (Rick)

While some of the men indicate being close with friends, others indicated that their AS significantly changed their lifestyle that resulted in a loss of friends.

I think it's got to do with me just changing. Cause I just didn't want to go out and party that much anymore . . . cause it's not comfortable for me to be in those areas. If I'm not at home then I can't get comfortable . . . And friends, you know, after refusing so many times, just stopped calling. Right, cause they know that I can't do the stuff anymore so they just don't bother with me . . . and eventually stopped phoning after I didn't go to so many parties. (Les)

These changes had a strong impact on the informant's lives and resulted in changes to their activities. In some cases, their AS has forced them to transition to the next stage of life.

Uh, well, you know, it kind of sucks but on the other hand, I'm kinda used to it and I don't really need people like that who just want me to party and stuff. I don't need that anymore, I'm too old for that. Kind of want a more laid back life now . . . but it sucked at the time. It sucked at the time for sure. But now it doesn't really bother me. (Les)

The informants indicated that intimate relationships were important source of support to them particularly given that these intimate partners were most likely to observe the daily stressors that can occur with AS.

There's nights when I can't, you know, even just going out somewhere sometimes, like sometimes I gotta change my mind halfway through you know. We got plans, you know, let's go do this, get halfway there, I gotta go back. Or, you know, not even get out the door and I have to change my mind or we'll talk on the phone at lunch and make plans for supper and I gotta tell her no. That really affects, you know, us a lot cause we're not getting our social time together right? We're not getting our going out, what couples do. (Les)

Not all the men were able to discuss the impact of AS on their functioning and a few noted their desire to improve their communication in this area.

Well I wouldn't say that [my girlfriend's have] all had a good understanding of it, but they've all kind of known something's been going on but . . . I guess I am growing to . . . have a better understanding that it's important to let the other person know what you're feeling even if it's something that even if it's something. . . that is not bothering you, or you don't necessarily want help with, it's just important I suppose, communication. (Tim)

These relationships, whether they are with friends or an intimate partner, are important elements of their broader participation in social roles. Despite the informant's ability to participate in social roles, there were significant barriers reported.

Summary

The themes arising from the interviews indicate that the informants have a strong affinity to western hegemonic masculinities. These men have a strong desire to show that they are capable of living a normal life that is fulfilling and have a strong need to exert control over their lives, which occurs through a variety of means. Work was also shown to be of high importance to these men that was shown through their desire to have and maintain a career. The men's relationships with their health care providers were more complex, while they wanted the external world to perceive them as capable and independent (i.e. normal), they sought validation from their health care providers that there were ill and required treatment and attention. Finally, the informants reported on their limits around informational support and the importance of their ability to receive support as well as their desire to receive it.

Chapter 5: Discussion

The following chapter highlights the key findings of the current study and how it relates to the existing literature through an examination of several topics important to the informants: masculinity, normalcy, control, and barriers. Furthermore, this chapter provides suggestions for Health Promotion Specialists and members of the clinical teams who care for men living with AS on potential strategies for improving care. Finally, there will be a discussion of the limitations of this research as well as the future plans for how it will be communicated with members of the AS community.

AS, as a chronic condition, falls into a category of “invisible” diseases. While the person with AS experiences medical difficulties such as pain, fatigue and mobility impairment these are not clearly apparent to others. In other invisible diseases such as chronic headache, COPD, and diabetes various authors such as Gysels and Higginson (2008) and Lonardi (2007) have noted that if desired, the invisibility of the disease allows the person to conceal impairment and outwardly portray health and strength. Despite some positive aspects, invisibility is not always desirable as it presents some barriers to seeking appropriate information, support, social and work accommodations (Joachim & Acorn, 2000; Lonardi, 2007). An invisible disease, such as AS, in combination with western hegemonic norms presents young men with a unique set of circumstances that affects their daily lives.

The men in the current study adhered to western masculine hegemonic norms that proscribed their daily coping with AS. Smith (2006) indicates that physical toughness, self-reliance, and stoicism are traits that represent Western cultural masculine norms. These norms further emphasize the importance of being seen as independent, normal, and

in control of their lives in their work and personal relationships; characteristics identified by Courtenay (2000) who examined gender differences as they relate to social structures and experiences and cultural representation of gender. Adherence to these gender norms created barriers to seeking information and additional support that might make their daily lives easier, particularly around the pain and discomfort associated with AS. Similarly, Davis et al. (2011) confirmed the importance of gender norms in their research on social role participation.

I'm a Man: Young Men With AS see Themselves Primarily as Masculine

The informants' sense of masculinity is at the core of each of their life worlds. As Connell (1995) indicates masculinity, the behaviours and practices that men and women engage in with respect to their body, personality and culture, derive from the male body. When this masculinity is challenged through disability, men are forced to re-evaluate their lives and re-invent themselves as men (Smith, 2006). The following discussion highlights masculinity and how it relates to gender norms as well as the importance of masculine role participation.

Masculinity. While there is a core group of masculine traits that seem to be consistent over time, the concept of masculinity and how it is defined is in a constant state of fluctuation (Connell, 1995). Masculinities are closely defined by social norms that are ever changing, creating generational differences in behavioural patterns, expectations and possibilities. The notion of masculinity is firmly rooted in past behaviours, yet over time there is a gradual shifting of these norms resulting in newly emerging masculine roles.

Cooper (2000) discusses the conceptualization of masculinities and their defining

characteristics. His research is concerned with the population of young men who were once defined as “nerds” in their younger years but have gone on to be highly successful and participated in the technology revolution (Cooper, 2000). Masculinity for this population is more often measured against the number of hours worked in a week as opposed to “out-machoing someone” through more traditional masculine characteristics such as physical size and assertive behaviour (Cooper, 2000, p. 382). The shifting of masculine norms is predicted, to some extent, by the social roles that men participate in.

Social roles are not separate from gendered or masculine roles. They are intertwined at the deepest level. According to Bates, Hankivsky and Springer (2009), “the ways in which gender shapes men’s health depend as well on its intersections with other social and structural locations” (p. 1003). Masculinity, and participation in masculine roles, was found to be highly valued in this research.

Participating in masculine roles ensures that young men are accepted by their peers and conform to societal expectations. However, adherence to these roles can be challenging for people living with a chronic disease (Davis et al., 2011). Some of the challenges outside the workplace faced by men with AS were summarized recently by Davis et al. (2011) who measured social role participation and the impact it has on health related quality of life. They found that participation in social roles for people living with spondyloarthritis, including AS, is compromised because onset is often during the third to fifth decade of life – the formative years for work, relationships and other key societal roles. Their AS informants reported restrictions in their recreation, community life, employment, intimate relationships, and family relationships suggesting that people living with AS are struggling with their connection to society in general. This failure to

connect to general societal roles undermines their ability to situate themselves in society as men. This connection was not a concern for the informants in this research. The informants in this study reported connecting well to masculine societal roles. The reason for the difference between this study and that which Davis et al. found is not apparent. It may be that the informants in this study were more closely connected to their intimate partners and, therefore, felt a closer connection to their societal roles in general. It may also be that the size and homogeneity of the sample in this research did not match the participant demographics in the Davis et al. study. Perhaps most significantly the young men in this study had not experienced significant disability from their AS and therefore had few limitations. In order to fully understand and appreciate the masculine roles these men assumed it is important to examine the underpinnings of gender.

Gender and, more importantly for this discussion, gender roles are widely disputed in the literature with significant variation between different groups such as evolutionary psychologists who believe that gender roles emerged from the amount of time women spent in gestation and the selection of a partner (Wood & Eagly, 2002). Conversely, social constructionists “emphasize societal role assignments and self-selection into social roles as the primary determinants of behavioural sex differences” (Wood & Eagly, 2002, p. 700). More recently, Wood and Eagly (2002) have presented a blended model of these perspectives that highlights a biosocial approach where the social roles of the sexes are embedded into social and ecological contexts. This biosocial approach takes into account the Western norms and traits highlighted by Smith (2006) and Courtenay (2000).

These norms are challenged when men are faced with a disability, such as AS

because they can no longer perform the same daily activities or maintain the same intensity that they once did, whether this be at the workplace or in their leisure activities. Therefore, each man must decide on one of three approaches, as described by Connell (1995), to continue to see himself as “being a man”. Each man could choose to “reject” the hegemonic norms of his culture, those norms that are held typically by other men, to which he once ascribed (Connell, 1995). Men who choose to reject the masculine hegemonies will often criticize those who continue to measure themselves against that standard. This rejecting process is difficult, as it requires a shift in deeply held values and behaviours. Rejecting previously held masculine norms was not evident in this research.

Secondly, each man could choose to “redouble” his efforts to achieve the same level of masculinity. Redoubling means applying additional effort to continue to achieve the standards that are set by the “average man”. This can be challenging, since men living with AS, or another chronic disease, often have physical barriers to overcome such as pain and discomfort. While redoubling was not as abundant in this research, there was evidence of such an approach. Some of the informants participated at work in the same way they had done previously such as returning to work from long-term disability and working in a position that required intense physical labour. This approach was not possible for all of the men due to the severity of their disease or the type of medication they were taking.

Thirdly, in Connell’s discussion of the impact of disability on masculinity, he may choose to “reformulate” (Connell, 1995). Reformulating is the process where men modify the pre-existing hegemonies to a new standard that is more achievable. For example, a man who was a weightlifter may have once been able to bench press 250 pounds. After

being diagnosed with a chronic disease such as AS, he has reformulated his masculinity into a new set of norms, and now still expects to be able to lift weights but does not expect to be able to achieve the same weight.

Reformulation was the primary approach taken by each of the men in this study. The choice to reformulate is consistent with the young adulthood literature. In this study the men showed a clear need to align their behaviours with western hegemonic masculine roles most probably, because of their ages, they still identify as young men. As Connell (1995) points out when discussing physical masculine norms, this is likely to change as men age because older men are not expected to achieve the same physical standards as they once did.

In this study, one path to reformulating masculinity was through physical activity. The informants spent a significant amount of time each week playing sports, running, swimming, going to the gym, and riding their bikes engaging in activities that Shuttleworth, Wedgwood and Wilson (2012) say are most often associated with “fighting like a man” (p. 185) to maintain their level of masculinity. At first look, none of these men would appear to be living with a chronic disease; however, on closer examination their actions show that they have had to redefine what success is for their physical activity levels. However, the desired outcome of their physical activity is not necessarily as it might be for other young men, the shaping of their physical bodies, but rather pain relief to allow for a good night’s sleep or to minimize the effect of their disease on day-to-day life. Since physical activity is an important element of the treatment and management of AS, being aware of the reformulation of activity levels is important when the medical care team considers the physical activity parameters for young men with AS.

Physical activity was not the only arena for reformulation; reformulation occurred at the workplace as well when some informants moved toward part-time work to create sustainable solutions for their incomes, because the workplace is one of the key venues for preserving masculine roles. In this study, reformulation occurred in the workplace where, despite their AS, the men strove to be normal.

Importance of work. Much research has been conducted about the importance of work for men in western societies (Helms-Erikson, Tanner, Crouter & McHale, 2000; Helms, Walls, Crouter, & McHale, 2010) and their participation in work (Boonen, 2006). Boonen (2006) defines participation at work as multidimensional, comprised of the ability to perform both paid and unpaid work. It was striking, in this study that all of the men described aspects of their lives in the context of their working situations and how they participated in them. Men's sense of participation at work is closely related to their western hegemonic masculine role of being a provider.

As Helms et al. (2010) noted in their study of dual earner spouse roles, men are reluctant to relinquish the role of the breadwinner and the "psychological responsibility to provide" (p. 568). This male role for providing is also noted in research involving spouses. In their research on dual-earner wives orientation to work and family life, Helms-Erikson et al. (2000) found that women were ambivalent about assuming the role of breadwinner and provider. Furthermore, they report that when the women earned more than their male counterparts, they generally still did not view themselves as providers or breadwinners for their families (Helms-Erikson et al., 2000).

The role of provider / breadwinner takes on many different forms depending upon the men's circumstances such as responsibility for self alone or responsibility for spouse

and children. Despite the variance of circumstance, the informants in this study valued highly the role of provider. Unsurprisingly, this becomes most obvious in the workplace where participation is closely associated with masculinity and independence (Boonen, 2006). Although not all of the informants in this study were working, they all identified that work, and the subsequent ability to provide for themselves, their partners and their families and to see themselves as adequate providers, was important. This perception of self as a provider is consistent with the literature in the field of masculinity as men desire to participate at work and be seen as independent through their ability to provide for themselves and others (Boonen, 2006; Helms et al., 2010).

The role of provider and how men are able to fulfill that role is at risk when faced with a chronic disease such as AS. As the health status changes, the men reformulate their masculinity (Connell, 1995; Smith, 2006). In this study the reformulation of masculinity at work included moving to part-time work, going on long-term disability, or being absent from work due to pain levels or medical appointments. This reformulation was not viewed negatively by the informants, but rather was seen as an important step to ensure their continued participation at work. There was, however, an effect from the AS on informant's comfort with disclosing / discussing their AS at work.

The need to see themselves in these typical western masculine roles resulted in some secretive behaviours. For example, most of the informants showed a reluctance to talk openly about their AS at work because they did not want to stand out as "different" in the workplace. They wanted to fit in and be recognized as strong capable men who were not hindered by their disease. There is a significant amount of research in the field of disclosure in the workplace that is valuable for this study.

Verakamp, van Dijk and Kroll (2013), in their study on workers with a chronic disease, report that diseases that are invisible in the workplace to both co-workers and supervisors, “may contribute to misunderstandings” (p. 410). The invisibility of their disease confronts workers with a decision of whether or not to tell their co-workers and employer (Verakamp et al., 2013). Beatty and Joffe (2006) indicate that this decision is a risky one. In their research paper on the career effects of chronic disease, Beatty and Joffe (2006) report that the decision to disclose can result in negative long-term effects in the workplace with co-workers changing their view of the person permanently.

In this study, informants rarely discussed their disease with people outside their close network of friends and family. They indicated being most uncomfortable disclosing their disease to work colleagues because they did not want to be seen as being weak. In their words they did not want to be pitied, or be seen as being unable to carry their workloads. This trait of limiting disclosure for fear of being seen as weak or not being self-reliant is consistent with western hegemonic masculine norms and existing research in the field of self-disclosure at work.

Corrigan and Watson (2002) noted that for people with chronic illnesses disclosure is more likely to occur in the workplace if there is an environment or culture of openness or if someone else with a chronic disease has disclosed. Conversely, if the culture in the workplace is not open, people are less likely to disclose their disease. In this study, those who did disclose were most likely to refer to the openness at their workplace; that it was “like a family”, while those who did not feel comfortable at work remained private about their AS. Since disclosure generally has positive health benefits (or at least reduces negative impacts), one challenge for those interested in disability in the

workplace is to create environments where disclosure can take place without negative social consequences, especially when workers who have been trained in the required workplace skills are valuable to the company.

Despite a strong effort to minimize disclosure to co-workers, most of the informants were required to disclose their disease to some of their colleagues due to illness or time away from work for medical appointments. Despite strong efforts to avoid lost time at work, the informants indicated that there were days when they had to take time off from work for medical appointments or because they were feeling ill. This is a common problem for men living with AS (Boonen, Brinkhuizen, Landewe, van der Heijde, and Severens, 2010). As Boonen et al. (2010) note, AS symptoms often interfere with the ability to work effectively resulting in poor presenteeism rates at work.

Presenteeism is closely linked with the perceived performance of an employee and the informants in this research were focused on having a successful career. In this research, as in the larger work and chronic illness research, the informants pushed through the difficult times at work to ensure they were in control of their disease, despite struggling with daily tasks. In their research on sick leave, presenteeism, and disability, Boonen et al. (2010) also report that men with AS have slightly lower rates of employment than their healthy counterparts, yet have a significantly higher rate of partial work disability. Their research further suggests that men with AS are making strong efforts to stay employed and go to work, yet they are struggling to complete their work roles. The men in this study validated this research through their focused effort on maintaining their careers despite obstacles such as having a physically demanding job.

While presenteeism is important to both employees and employers, performance

in the workplace is valued differently for men and women (Venkatesh & Morris, 2000). Venkatesh and Morris (2000), conducting research on gender roles in the workplace, found that men were most concerned with any changes that had a direct impact on their overall performance, while women in the study were more influenced by the subjective norms in the workplace, which includes adhering to the defined practices of their environment. Gender and the sex differences that exist between men and women are a strong predictor and influence on their behaviours. The men in this research displayed a need to perform well in their workplace, despite their AS and presenteeism challenges.

The importance of work participation extends beyond attendance, presenteeism and the ability to financially provide for oneself and their family. Participation at work is closely linked with workplace social support which is defined by Kossek, Pichler, Bodner and Hammer (2011) as “the degree to which individuals perceive that their well-being is valued by workplace sources, such as supervisors and the broader organization” (p. 292). Workplace social support is related to the workplace environment that exists for employees, supervisors and the organization (Eachin & MacEachen, 1998). In their qualitative research on small businesses and health-related employee experiences, Eachin and MacEachen (1998) found that social relationships between employers and employees affected worker health status. This was particularly true when employees felt that they were “treated as a person” (Eachin & MacEachen, 1998, p. 901). While most of the informants in the current study did not disclose their AS to their work colleagues, this did not preclude them from participating in social interactions at work. While the informants did not openly discuss the importance of their work in terms of social interactions, it is plausible, and even likely, that it fulfilled an important component of their social lives.

Participation in work roles and the appearance of normalcy was important to the men in this research.

Trying to Maintain Normalcy: Young Men With AS see Themselves as Normal

The informants saw themselves as normal young men who “happened” to have a chronic disease. While the focus of this research was on their AS and the effect it had on their lives, it quickly became obvious that their disease was not central to who they are. They see themselves not only as men but as *normal* young men. They accomplish this by making decisions and participating in activities that allow them to fulfill normal masculine roles, despite the potential negative physical effects these decisions might engender.

Decisional balance. In examining the ways in which people make decisions, Prochaska et al. (1994) indicate that the decision making process is structured around a thorough scan of the factors upon which decisions are based. They suggest that making certain decisions, while seemingly negative to the outside observer, has benefits to those making the decision. Using the Transtheoretical Model of Behaviour Change that posits five stages of change: precontemplation, contemplation, preparation, action, and maintenance, Prochaska et al. (1994) developed a Decisional Balance Theory. Decisional balance is a measure of attitude that determines how individuals weigh the consequences of specific behaviours in terms of pros and cons (Geller et al., 2012). Other researchers have subsequently used the model for a variety of illnesses and behaviours although there does not appear to be any research examining decisional balance and arthritis, or more specifically AS. Nevertheless, the application of this theory in this research is a reasonable approach given the commonalities between chronic diseases, challenges with

medication adherence being one, and the success of this theory in these areas.

The informants consistently showed that they made decisions they knew would negatively affect their health such as spending too much time hunched over a computer and engaging in social events at times and in circumstances that could be detrimental to their health. This need to live as normal a life as possible allowed the men to negate AS as a limiting factor, and thus feel masculine. This decisional balance was also evident in to whom the informants disclosed and discussed their AS.

Discussing/ Disclosing AS. Funir, Leka and Griffiths (2006) define self-disclosure as revealing personal information about oneself to another. The decision to disclose a chronic illness, generally, not only at work, is a complex one that is influenced by a number of factors including stigma, type and severity of illness, and access to support (Funir et al., 2006).

Joachim and Acorn (2000) in earlier work discussed this very issue in their research on the stigma associated with the chronic disease COPD. They confirmed patients' desire to keep aspects of their disease hidden. Joachim and Acorn (2000) describe the different dimensions of stigma and posit that concealability (i.e. someone's ability to conceal his / her disease) and disease course play an integral role in the stigma of chronic disease. Concealability is described as "a critically important dimension of stigma: [because] visibility plays an important role in producing negative social reactions" (p. 244). Visibility in AS may occur with disclosure and, therefore, the potential for negative social consequences such not being accepted by loved ones as having a legitimate chronic illness given the associated stigma of arthritis as a disease found only in the older population.

The findings in this study are consistent with both the evidence presented by Gysels and Higginson (2008) suggesting that there are benefits to not disclosing. In agreement with Joachim and Acorn (2000), one benefit that Gysels and Higginson (2008) report is that invisibility allows the person to gradually adjust to the condition over time. Despite this advantage, non-disclosure can be detrimental to the health and well-being of those with a chronic illness. The current study noted just that difficulty. The informants in this research struggled on one hand to maintain the invisibility of their disease and on the other to reveal the disease so they could make appropriate adjustments both at work and in their larger social lives. Other research has reported informants saying that if they had a condition with outward signs and symptoms visible to co-workers, friends, and family, then it would be easier for them to be more open to discussing/disclosing their AS (Corrigan & Watson, 2002).

While, as previously discussed, disclosure at the workplace was challenging, disclosure to family and friends was much more likely, although there were limitations here as well. Most of the informants openly discussed their AS with close family members; however, they did not necessarily rely on them for assistance in managing their disease. Despite general disclosure, there were some notable differences about the degree of disclosure based on the nature of the relationship. While all family members of the men knew about their diagnosis, not all were equally intimately involved in understanding the degree to which the diagnosis impacted the daily lives of their sons or brothers. Some of the distance the informants created with their family members may be explained by adherence to western hegemonic norms valuing independence in men.

Being independent. As Sathananthan and David (1997) discuss, men somewhere between 18 and 39 move away from relying on parental advice and support to focus on support from their intimate partners, or in this research, their girlfriends. While most of the men in this study reported a strong bond and appreciation for their parents, they clearly indicated their independence by managing their AS and lives on their own. While none of the informants indicated their intention to avoid discussing their disease with their parents, they purposefully kept the management of their disease to themselves or their intimate partners.

Allen, Channon, Lowes, Atwell and Lane (2011) report in their research into the shifting roles of parents with children who have diabetes that the primary goal is to establish independence in their children so that they can self-sustain. However, Allen et al. (2011) further report a current trend where “many young people do not move neatly from a state of dependence to independence” (p. 994). They indicate that there are often false starts where the children leave the home for a period of time and then return. Most of the informants in this research did not show this trend. In fact, most of the informants were proud of the fact that they were able to show their independence by moving away from their parents. While none of the informants in this research were children, many of them were young men who recently transitioned out of childhood.

Sathananthan and David (1997) indicate that the independence that men seek is realized through several rites of passage “the completion of education, starting of employment, financial independence, leaving home, and the possibility of making a contribution to society” (p. 355). These informants are young men who are establishing themselves in their careers and relationships and, therefore, gaining independence despite

their chronic condition.

This growing independence and separation from their parents was a common theme. While the transition from their parents' guidance, protection and advice is a key milestone in their growth, there is also evidence of the changing relationships with friends that signifies a shift in their stage of life (Sathanathan & David, 1997). All of the informants reported that they had, at one time or another, made decisions about whether or not to spend time with friends. These decisions were made for a variety of reasons and indicate the changing relationships at this age. As has been reported in the research, much like parental relationships, young men tend to shift away somewhat from the traditional close friendships when they become romantically involved with a woman. This shifting of priorities is also an indication that they are seeking independence and "growing up" (Allen et al., 2011; Sathanathan & David, 1997). Similar to young men without a chronic condition, the informants expressed their independence through a variety of behaviours including their decisions to seek medical, informational, and emotional support.

Interactions with physicians. Courtenay (2000), Mahalik, Lagan and Morrison (2006) and Levant, Wimer, Williams, Smalley and Noronha (2009) all report in their research on masculinity and help-seeking behaviour that masculinity may be a barrier to psychological help-seeking that may influence risky health-related habits and also a barrier to physical help-seeking that can result in serious increases in avoidable morbidity and mortality. As was evident in this research, at least one of the men experienced permanent damage from AS that might have been prevented with earlier medical assistance. In this instance adherence to western hegemonic norms, showing that men

more than women are also more likely to avoid seeking medical attention, despite a need to do so (Courtenay 2000), is a barrier to successfully managing chronic illness (Mahalik et al., 2006; Levant et al., 2009). This is particularly interesting when considering that men with chronic conditions require medical assistance.

As Courtenay (2000) and Smith (2006) also found, not only are men less likely than women to seek support from a health care provider, they are also less likely than women to perceive their need for assistance from health care providers. Smith (2006) postulates that this reluctance to acknowledge personal and health problems stems from the fact that discussing health problems forces men to engage in activities that are more closely associated with women including giving up power and control, seeking support, and acknowledging their own weaknesses. The reluctance identified by Smith was observed in this current research. Rather than admitting to a potential illness a few informants early on, indicated they were “wishing away” their symptoms (Mahalik, et al., 2006) while others who finally did seek medical assistance were challenged to find an effective way to interact with their health care providers and to define their roles with their providers. These interactions tended to fall into two distinct categories differing by the seriousness of AS.

Those with milder signs and symptoms reported dissatisfaction with their annual visits to see their rheumatologist while those with more serious manifestations of AS felt that their appointments were helpful. Despite this apparent dichotomy, both groups were displaying masculinities that would further their self-perception of being normal.

Informants from this study who said they did not benefit from a visit to their provider, mostly those with milder forms of AS, expressed a duality of feelings where

they wanted to feel like normal young men who did not have a chronic disease, while simultaneously needing to be validated by their health care provider that their disease was serious. When indicating they did not benefit from the appointments, they mentioned the repetitive nature of the visits where they must “touch their toes and have x-rays”, feeling that these tests were not a good use of their time. They also indicated that they felt as though they were “second class” AS patients because they were not receiving clear advice or having changes to their medications. In this particular role, the informants wanted to feel validated in their illness; they needed to have their provider confirm that their pain and discomfort were legitimate.

These findings are entirely consistent with those of Frank (2013) who observes that “certain expectations come with identifying oneself as sick” for both the patient and the physician (p. 19). Frank further reports that the “role of the doctor is to provide legitimation that the patient actually is sick and thus entitled to the ‘permissive’ aspects of the sick role” (Frank, 2013, p. 19). Frank’s research is based on the seminal work of Parsons (1978) and the sick role. Parson’s sick role conceptualization was originally constructed around acute illness and “emphasized how these expectations include certain rights and responsibilities which serve to change the sick person’s orientation toward other people in society and vice versa” (Crossley, 1998, p. 509). Parsons believed that “social roles govern the behaviour of those designated ill, channeling [sic] sick people toward medical professionals and through the health care system” (Perry, 2011, pp. 461-462). As the burden of chronic illness has grown since the middle of the 20th century when Parsons developed the sick role concept, there have been many critiques about its relevance (Crossley, 1998; Perry, 2011; Varul, 2010). The central argument in these

critiques is that the sick role is centred on a short term illness that has a specified endpoint, whereas chronic illness is ever-present (Varul, 2010). However, there is recent research that argues for another examination of the sick role and how it might be applied to chronic illness (Perry, 2011; Varul, 2010). Perry (2011) suggests that the advances in the field of mental illness and the growing understanding of the importance of social networks and social support for people living with mental illness support the concept of rights and responsibilities that are inherent in the sick role. Parsons (1978) himself argued that the sick role was applicable to chronic illness through a commitment to attempting to recover and maintain a state of health through a strict regimen of treatment. Varul (2010) states that “while compliance with sick role expectations is still required, it no longer offsets the diminished contributions in normal roles” (p. 82).

One concept that has been problematic for the sick role is the notion of recognizing the physician or professional as the keeper of all the knowledge concerning treatment and management of the illness (Varul, 2010). Much of the management of chronic illness has been focused on self-care by the patient, minimizing the imbalance between the roles of patient and provider (Lorig & Holman, 2003). Despite minimizing this imbalance, there remains a role for the person living with a chronic illness to seek assistance from a professional before growing his/her independence (Varul, 2010). The informants in this research recognized this need for advice and support from a professional, yet some of them struggled with the validation of their illness that seemed to be questioning their need for support.

While aspects of Parson’s (1951) original theory have been disputed, the role of the physician in legitimizing the illness for the patient remains unchanged. The findings

of this research are consistent with those of Donovan and Blake (2000) who, in their research on reassurance of clinicians to people with mild arthritis, found that patients do not wish to be reassured that their disease is mild or in early stages. Rather, patients wish to be validated that their perceptions of their difficulties are legitimate despite presenting themselves to the external world as “normal”. The work of de Souza and de Lima (2007) tackle this concept of dynamic polarity defining it as positions “whose extremes are health and illness; and at the same time a normative activity, which indicates one of the poles as wanted and the other as unwanted” (p. 161). It is further noted that this polarity exists within the same person and cannot be separated, nor should it be attempted because they are a part of a whole (de Souza and de Lima, 2007). Thus, while from the rheumatologist’s viewpoint, a quick medical visit with toe touching and no change in medications seems very positive, from the patient’s viewpoint it creates frustration.

In contrast to those patients with milder AS, the men in this study who reported excellent interactions with their rheumatologists and other health care providers had more serious disease, more medication changes, and more interventions overall. Using Donovan and Blake’s (2000) findings as a framework, this additional attention from the clinician as a result of more medical intervention has validated the informants’ perception that their AS is serious and in need of the rheumatologist’s attention. Therefore, they feel like “normal” patients with AS, or at least how they perceive that a patient should be.

Despite some differences between this research study and the broader literature, there remain consistencies with the challenges related to men and their interactions with the health care system and its professionals. As was evident through the interactions with health care professionals, as well as the masculine norm of normalcy, there was also the

need for control.

Do What I Like to Do: Young Men with AS see Themselves as in Control of Their Lives

The informants in this study showed a strong desire to be in control of their lives. Courtenay (2000) reports that a strong sense of control is consistent with western hegemonic masculine norms. The informants want the power and control over their disease to lead a normal life. Research indicates that people with chronic diseases such as arthritis desire to have personal control because it can help to alleviate or undercut feelings of helplessness or incompetence (Tennen, Affleck, Urrows, Higgins, & Mendola, 1992). In this study, control was manifested through seeking emotional and informational support and in managing their AS.

Emotional support. Informants reported multiple roles in their relationships: son, friend, and boyfriend. Each informant and his family have individual nuanced relationships shaped over many years. This was particularly notable in the differences observed between the younger and older cadre of informants in their relationships with their parents. The younger informants were more closely connected with their parents and were more likely to discuss their AS with them; whereas the older informants preferred to manage their AS independent of their parents not discussing details with them. The intimate relationships between the informants and their girlfriends indicate that some of the men confided in their partners. As can be expected for their stage of life, the relationship between some of the informants and their friends has also changed over time resulting in some challenges to seeking emotional support. These challenges, however, do not appear significantly different for young men with AS than for young men without

chronic conditions who may require support (Eriksson & Lauri, 2000). Practically speaking it is important for the medical care team to appreciate that these men, when they do require support, are more likely to seek it from intimate partners than from other sources such as support groups. Attending a support group may challenge these men's sense of control; therefore, including intimate partners in the support process would be desirable.

While emotional support is important to young men with AS, it is critical that it comes from the right person; however, as previously noted, seeking support is often double edged; it can be seen as weakness or it can contribute to becoming more informed which in turn results in greater control. One of the areas, in this study, where control was manifested, was around choices about informational support.

Informational support. Informant's information seeking, that is people's ability and desire to access information, about AS occurred by reading online, reading books, or talking to their doctor. Informants reported controlling how much they wanted to know about AS.

All of the informants acknowledged that they had at least a basic understanding of their disease from their rheumatologist and other health care providers they had interacted with over the years. However, a barrier to learning more about their disease was the emotional discomfort, including self-described depression, and distress it evoked. Tice, Bratslavsky, and Baumeister (2001), report that a person who is upset "ceases to care about pursuing positive, desirable options and, therefore, becomes willing to contravene his or her own normal patterns of goal pursuit and healthy, constructive behaviour" (p. 55). The research by Tice et al. (2001) indicates that emotional distress plays a significant

role in people's ability to access informational support. One way to diminish or to ameliorate that distress is to avoid seeking additional information. The informants in this study reported that the avoidance of new information (including advice on their condition) furthered their sense of control about managing their illness. The mental strain and struggle from learning more about what could go wrong with them was restricting their independence and sense of control and, therefore, their ability to feel masculine.

Other informants demonstrated their control by learning as much as they could about their AS. These men took comfort in the fact that they felt as though they were doing everything they could to manage their disease, and not simply relying on medical professionals to make decisions on their care and treatment. In these cases, the acquisition of information may have been a defence mechanism. Some of the men read books, searched online, and asked questions of their providers on key topics such as medications, smoking, drugs, and exercise. This information enabled them to feel more in control because they felt empowered to self manage their disease and participate in the decisions relating to their care. Acknowledging the various approaches to information seeking, or lack thereof, provides some important directions to the medical care team including health promoters, ensuring those with AS have sufficient resources outside the medical appointment. This also applies to non-medical information and coping strategies.

Disease management approaches. As well as searching for information about their diseases, self-management involved application of informants' personal beliefs about their disease and by extension, their lives. It should be noted here that the informant's self-management approaches were complementary to the medical management of their AS as recommended by their health care team. As reported in the

findings of this current study, some of the men believed that they could best manage their disease in a physical manner, while others believed it could be done through positive thinking or some combination of these two primary approaches.

Self-management approaches for people living with chronic disease, and more specifically, arthritis, are well represented in the published literature (Lorig & Holman, 2003; Lorig, Mazonson, & Holman, 1993). Most widely known are those self-management support programs that use the Stanford Model (Lorig et al., 1993). The two most common programs are the Arthritis Self-Management Program (ASMP) and the Chronic Disease Self-Management Program (CDSMP) (Lorig & Holman, 2003). These programs provide educational supports to increase self-efficacy for people living with chronic diseases by focussing on physical activity and managing disease through positive thinking (Lorig & Holman, 2003). It was interesting that the informants in this study arrived at these two primary approaches for managing their disease despite none of them having attended any programs or classes with that emphasis. They reported that they learned their self-management approaches through personal experience and advice from their health care providers, an important finding for health promotion specialists.

The chronic disease literature reports that successful self-management is closely associated with self-efficacy (Jerant, von Friederichs-Fitzwater, & Moore, 2005). Jerant et al. (2005) mention “self efficacy [is] associated with more optimal self-care behaviours” (p. 301). Interventions such as the ASMP and CDSMP can strengthen self-efficacy that leads to improved health outcomes (Jerant et al., 2005). The most common self-management programs are structured to teach problem solving skills rather than simply relay information in the more traditional manner (Bodenheimer, Lorig, Holman &

Grumbach, 2002). Verakamp et al. (2009) in applying these to the workplace, report that “there is evidence for the effectiveness of empowerment-based interventions” that encourage people to seek their own solutions when faced with a problem in the workplace (p. 399). However, it appears that self-management programs are not the only way people learn to manage their disease. Auduly, Asplund, and Norbergh (2012) indicate that self-management is a skill that can be acquired over time through a series of steps that shift as the individual becomes more accustomed to living with his or her illness. With this experience, people living with a chronic disease begin to assimilate self-management practices into their daily lives. The informants’ descriptions of their experience in the current study are consistent with the findings of Auduly et al. (2012). Over time, these informants learned what worked for the management of their disease and built those practices into their daily lives. This practical approach of learning through experience has impacts for Health Promotion Specialists and medical care providers as well.

In summary, the informants in this research perceived themselves as in control of their lives. This sense of control was an important aspect for these men to feel masculine. In addition to feeling in control of their lives and masculine, the informants were impacted in their daily lives by a variety of barriers that challenged their sense of masculinity, normalcy and control.

Young Men with AS Face Barriers

The second question in this research project explored the barriers (i.e. obstacles that prevent the informants from accessing the care they need) that young men with AS face in accessing services and supports. The informants in this study discussed several

barriers they faced in their day-to-day lives such as pain and discomfort from their disease, side effects and other challenges from their medications, barriers to their futures as fathers, and challenges associated with their own masculinity.

Pain and discomfort. All of the informants indicated that pain and discomfort were part of their lives and that their pain levels could range from none to quite severe and debilitating. While this pain may disappear from time-to-time, it is typically present and affecting their daily lives in some manner. Backman (2006) indicates that pain can have an effect on work, family life, and leisure. Psychosocially, people living with AS undergo significant stress in their lives which affects their ability to participate at work and in other social roles (Backman, 2006). This psychosocial stress is consistent with the current study, where all informants indicated that pain levels had some impact on their decisions to participate in social activities with friends and girlfriends as well as planning for their future in terms of a career and a family. While none of the informants in this study overtly discussed their pain as such a limiting factor, it was a consistent thread in much of their decision-making and governed how they handled their medications.

Medications. The informants also expressed significant challenges about use and impact of their medications. The medications were a significant barrier to these men as they contributed to potential or real physical side effects to the informants and affected their health care decisions. While the informants generally complied with their health care provider's instructions, at times they failed to adhere to their prescribed medication regimen resulting in some negative health consequences. Bayliss, Steiner, Fernald, Crane, and Main (2003) researched this phenomenon, reporting that medication adherence is a challenge for people living with chronic conditions, especially when the complexity of

the medications increases. The findings in the wider research are only partially consistent with the findings of this study. While most of the informants saw their medications as a barrier, they were prescribed a regimen that was relatively simple in both the number and frequency of their medications. The informants nevertheless struggled with adherence from time to time, so rather than the complexity of the regimen being the barrier, these men identified the side effects of the medication as most important. Medication adherence was variable over time for the informants in this study, yet their concern about their ability to participate as fathers was consistent.

Fatherhood. The informants indicated that there were challenges with family planning. The men in this study expressed some concern about passing along their AS to their children, despite medical evidence to the contrary. However, their greater concern was around their ability to interact with their children as both they and their children grew older – their ability to be fully-engaged fathers. While most of the informants did not have children at the time of the interviews, it was something that they had considered. They discussed how activities such as playing with them or coaching future teams would be negatively affected by their AS. This aspect of fatherhood is largely absent in the published literature.

Most of the literature on AS and genetics focuses on the presence and heritability of various genetic markers and does not appear to provide much evidence or advice for those with AS or their sexual partners about family planning. While there is some information about family planning for women with rheumatic disease it is very limited for men (Ostensen, 1991). This gap in the research on men's concerns about family planning and fatherhood is relevant given recent studies that explore the importance of

fatherhood for men and how this role is changing (Bates, Hankivsky, & Springer, 2009; Brandth & Kvande, 1998; Cooper, 2000).

Fatherhood and parenting roles for men have shifted over time and have resulted in higher expectations for men to participate in the lives of their children. Brandth and Kvande (1998) discuss how shifting cultural norms have encouraged and enabled men to be more involved in their children's upbringing. Paternity leave is an example of how society has responded to culturally normative shifts enabling men to play a more active role in the rearing of their children from a young age (Brandth & Kvande, 1998).

The informants in this current research disclosed their desire to be able to participate in the rearing of their children and were concerned about how their AS may be a barrier to that. While young men with AS have a responsibility to self-manage their disease, the medical care team and health promoters have an important opportunity to assist with these men's roles as future fathers. It should be noted that each of the men saw themselves as perfectly capable of raising a child in their current state, but they each assumed that their health would decline at some point. This concern about their participation as fathers clearly moves beyond issues of heritability. While the informants expressed concern about their futures as fathers, they also identified some of their masculine behaviours as impacting their health.

Masculinity. The informants' masculine behaviours and choices have shown themselves to be barriers to remaining as healthy as possible given their chronic condition. Skovdal et al. (2011) conducted research into masculinity as a barrier for HIV positive men in Zimbabwe and report that their informants felt they needed to be "in control, to have know-how, be strong, resilient, disease free, highly sexual and

economically productive” (p. 1). Furthermore, Skovdal et al. found that these traits were in direct conflict with their ability to be compliant with the recommended behaviours and norms of “the ‘good patient’ persona” (p. 1). This is further validated in the literature by Levant et al. (2009) in the research on masculinity and help-seeking. They indicate that masculinity itself can be a predictor of poor health choices. This is consistent with the findings in this research. The informants’ decisions that led them to feel normal and in control of their lives were, at times, poor health choices. As previously discussed, these decisions sometimes resulted in increased pain levels and reduced quality of life.

These barriers highlight the dichotomy among the informants in this research: they have made choices that enabled them to feel masculine, normal, and in control, and yet are impeded in realizing these roles by their choices. These barriers provide direction for health promotion specialists and future research.

Contributions to Practice –Health Promotion and Health Care Teams

The focus of this research has been on the experiences of young men living with AS and the barriers they face in their daily lives; however, this is also a thesis for a Health Promotion degree and, as such, is focused on what this research can contribute to the day-to-day management for both those living with AS as well as those providing care to them. The following section will explore the Health Promotion Model that was used in this research as well as the practical recommendations that have arisen from this work.

Health Promotion Model. This research used the Stages of Change Theory as its health promotion model (See Figure 1) that is “the central organizing construct of the Transtheoretical Model”, developed by James Prochaska (Prochaska & Velicer, 1997, p. 6). The Stages of Change Theory has been used throughout the health promotion

literature in the fields of diabetes, cardiac diagnosis, obesity and other chronic conditions (Boyle, O'Connor, Pronk, & Tan, 1998; Hellman, 1997; Suris, Trapp, Diclemente, & Cousins, 1998; Vallis et al., 2003). The theory presents five stages that people transition through when changing their behaviour: Precontemplation, Contemplation, Preparation, Action and Maintenance (Prochaska & Velicer, 1997). This theory focuses on delivering health promotion interventions for individuals and groups at the proper stage while considering the importance of integrating these interventions across multiple sites such as school, workplace, home, and community (Prochaska & Velicer, 1997). Given that this current study is a Health Promotion research project, this model can provide context for some of the decisions the informants have made at different points of their lives and for different aspects of their lives as well as ensure that health promoters and health care providers are considering appropriate interventions as recommendations for the field.



Figure 1: Stages of Change Model. (Pro-Change Behavior Systems Inc., 2013)

The informants displayed and discussed a variety of behaviours that placed them at different stages of behaviour change with respect to the management of their AS. It should be noted, that the stage of change for an individual is specific to a given behaviour and is not a reflection of their overall person (Prochaska & Velicer, 1997). For example, a person who is living with diabetes and obesity could be in the maintenance stage for the management of blood sugars through regular diabetes testing, yet be in precontemplation

for the management of his/her obesity. The informants in this current research may be placed in a variety of stages, depending on the behaviour that is considered; for example, one informant in this research was in the contemplation stage about returning to work, but was in maintenance for his physical activity levels. Accessing various stages can pose challenges for a more generalized health promotion approach, but will encourage a more specific intervention around behaviours in the AS population. The following discussion highlights the five Stages of Change and provides informant examples for each stage.

Precontemplation. Precontemplation is defined as “the stage in which there is no intention to change behaviour in the foreseeable future (Prochaska & Norcross, 2001, p. 443). Many of the informants reported challenges in adopting new behaviours that are associated with the management of AS including medication adherence, physical activity levels, and accepting or seeking informational support. These are examples of how, for a period of time in their lives, the informants were in the Precontemplation stage concerning the management of their AS.

Contemplation. According to Prochaska and Norcross (2001), “contemplation is the stage in which people are aware that a problem exists and are seriously thinking about overcoming it but have not yet made a commitment to take action” (p. 443). This stage was evident in this current research as one of the informants reported a desire to return to the work force, yet struggled with the steps to take to make that move.

Preparation. One informant showed some success with weight loss and returning to the work force for a period of time. This was not a long-term change but was an important step toward making lasting behaviour change that would see him lose the weight he desired and stay as an active member of the workforce. This is an example of

the informant being in the Preparation stage, a stage where individuals “are intending to take action in the next month and have unsuccessfully taken action in the past year” (Prochaska & Norcross, 2001, p. 444).

Action. The Action stage is where “individuals modify their behaviour, experiences, and environment in order to overcome their problems” (Prochaska & Norcross, 2001, p. 444). Some of the informants in this research displayed their ability to self-manage their careers by changing jobs or even moving to self-employment to ensure their AS was managed appropriately. This is an example of how the informants were in the Action stage.

Maintenance. Prochaska and Norcross (2001) define the Maintenance stage as “the stage in which people work to prevent relapse and consolidate the gains attained during action” (p. 444). This stage is exemplified best by the informant’s physical activity levels. Many of the informants in this research study showed a long-term commitment to physical activity as the primary treatment modality. The success of this approach was made apparent throughout the results chapter as this was considered by most of the informants to being the cornerstone of the management of their AS.

The Stages of Change Theory is an effective tool for health promoters to use when planning interventions (Prochaska & Norcross, 2001). This theory provides context for participant’s readiness to change their behaviour, which is an important aspect of planning the approach or strategy to encourage healthy behaviours. The subsequent discussion highlights the need for individual and group based approaches for successful health behaviour change in the AS population and how the Stages of Change Theory is useful for designing interventions.

Recommendations for Health Promoters and Health Care providers. The following discussion provides recommendations for people living with AS as well as those who support them. These recommendations highlight the relationship to the various Stages of Change in five areas: access to healthcare, informational/ emotional support, self-management support, adherence, and validating the sick role.

Access to healthcare. Much Health Promotion research and interventions focus on primary prevention of various conditions including chronic illness. Since AS is not currently a preventable condition, health promotion efforts must focus on secondary prevention (early detection) and tertiary prevention (improving or maintaining quality of life). In this study the informants highlighted their reluctance to seek medical assistance until their condition had begun to interfere with their daily lives. This avoidance of health care is not limited to men with AS but is generally recorded across the chronic disease literature (Addis & Mahalik, 2003; Courtenay, 2000). There are opportunities here for Health Promoters to use some of the social marketing techniques that seem to have been successful in other conditions such as colon cancer or in having young men engage in testicular self-examination (Shallwani, Ramji, Ali, Khuwaja, 2010). This secondary prevention approach targets men with AS who are in the Precontemplation stage through providing information to them when they may be prepared to read it. It is important for men in this stage of behaviour change to feel empowered to make the decisions about what information they want and how they want to access it. Short of shifting western masculine hegemonic norms, this behaviour change will be difficult to action.

Informational/ Emotional support. This current research found that information seeking about AS is either limited to clinic materials or based on internet searches it may

be useful for health promoters developing arthritis materials to focus on key points as well as to identify trusted online sources for not only AS patients but their families. Also, given that none of the men in the current study sought assistance from existing Arthritis Self-Management Programs there is an opportunity to develop some simple materials around self-management that may be useful. Given that the informants would need to be actively searching for materials online or engaged with their rheumatologist in discussing self-management, this approach is focused on men in the Preparation and Action stages. In these stages, men will need to access information-rich resources that will clearly outline their area of interest. Health Promotion Specialists can focus on working with key groups such as the rheumatology clinic team, the family physician and The Arthritis Society to develop resources that are focused on the needs of men with AS, rather than relying on traditional approaches that are primarily targeted at women.

One of the roles of Health Promotion in tertiary prevention has been to connect patients to resources for support groups such as those identified through the Self-Help Connection in Nova Scotia. Despite the success and popularity of support groups for certain populations, none of the informants in the current study sought outside support, therefore this strategy may not be effective. The longer term approach may be to change the cultural norms for help seeking but the more immediate approach could be to encourage partners of those with AS to be part of the information and emotional support system. Including them in the process is likely to be a good first step. Encouraging young men with AS to involve their partners to be active members in a support system is an approach that targets men in the Action stage of behaviour change, given that they are actively seeking care. This approach is important since the informants have already

demonstrated their capacity for behaviour change in one aspect of their lives and it is critical that this foundation be built upon for further improvement. Identifying where each man may be in terms of the various behaviours (physical activity, medication adherence, accessing health care) will be critical to selecting and recommending specific interventions to encourage access to both informational and emotional support.

Self-management support. This research may also prove beneficial to health care providers, specifically rheumatologists. As indicated above, these findings suggest that young men with AS are not interested in taking self-management classes. In Nova Scotia, classes offered by a variety of organizations and The Arthritis Society such as the ASMP, CDSMP, Your Way to Wellness (YW2W) and the Chronic Pain Management Seminar are often seen as the primary vehicle for learning self-management techniques. The young men in this research were more interested in learning through experience and chose to adopt their own self-management techniques. This suggests that providers need to consider this “learning by doing” process as a valid option for these young men. Cognizant that young men with AS are developing some of their own strategies, health care providers might highlight some of the potential physical harm that may result from certain exercises while encouraging their patients to find what works for them. Given that these young men prefer to explore a variety of strategies for managing their disease on their own, it would be reasonable for the rheumatology clinic, The Arthritis Society, or a related group to develop a program or class that would provide these men with an opportunity to be exposed to the various techniques and strategies that can safely be used. This type of program would appeal to the men’s preference of experiencing the different strategies as opposed to sitting down and talking about them in a group. While this

program would not stop the men from experimenting on their own, it would provide safer alternatives for them. The approach of developing an individualized self-management program is an example of appealing to men in the Action and Maintenance stages since the informants are actively seeking and trialing different techniques. Similarly, Health Promotion Specialists can employ such an approach to further men's knowledge and experiences in the management of their AS that are considered safe and effective options by the medical community that provides care for them.

Adherence. These informants also showed that they have struggled in the past with adherence and delays in treatment. This would indicate that health care providers should consider discussing the treatments and their side effects with the informants to find a balance between effectiveness of the medications and the likelihood of adherence. This approach highlights how young men who are struggling with their medication can step backward through the Stages of Change from Action to Preparation or even Contemplation. As Health Promotion Specialists it is important to develop strategies to avoid this negative behaviour change and encourage a move back to the Action stage in a proactive manner. This strategy of discussing treatment options, side effects, and adherence openly with the men is an important step in avoiding this backward movement through the Stages of Change.

Validating the sick role. Finally, this research has shown that the informants with less severe AS require validation of their "sick role" from their providers, specifically their rheumatologists. While most rheumatologists are taught and may believe that it is appropriate to "downplay" the severity of their disease in individuals with less severe AS, the informants indicate that this is not what they desire. They are seeking validation that

they are sick. While this may seem in direct contrast to their desire to be considered strong and masculine, it was reported as an important aspect of their appointment with the rheumatologists. This particular behaviour change (the Action stage) relates to the rheumatologists rather than the person living with the disease. Since the rheumatologists already perform patient counselling and this is simply an addition to the message they deliver.

Limitations of the Research

As with any research project, there are limitations that affect its scope and applicability. The four most important include recruiting research informants, completing the interview process, my inexperience as a researcher, and my impact as a male researcher on male informants.

In the proposal for the current study and in keeping with phenomenological inquiry, a sample of 10-12 participants was considered desirable (Creswell, 2003). Despite having a reasonable pool of potential research participants garnered from the Rheumatology Clinic patient database, after the quick initial response of six informants, the informant response slowed considerably. Several attempts were made through snowball sampling to increase the informant pool but in the end, seven men participated. Fortunately data saturation appeared to take place. Nevertheless it is unclear if an additional 4 informants may have altered the research findings.

Secondly the methods required an initial and follow up interview with each informant. One of the informants did not receive a follow up interview despite multiple attempts to reconnect with him. As a result, some depth to the data may be missing.

My inexperience as an interviewer may also have affected the findings. Upon

reflection, it may have been of value to conduct a third interview with the first few informants. As the interviews progressed I became more skilled at probing for experiences from the informants and the informants became more comfortable with me. Initially, there was some variability in my questioning and probing techniques. For example, in the first interview I followed my interview guide very closely because I was nervous about missing a question and I wanted to seem organized for the informant. In later interviews I was much more prepared for how I would conduct the interview and was more comfortable with the questions in the interview guide so the conversation flow more naturally and effectively. While this variability is common in first time interviewers, it should still be considered a limitation of the research.

Finally, it is possible that my being a male researcher may have affected the interviews with a group of male informants due to their desire to ensure their masculine identity was upheld in front of another man. I believe that while the informants were open with me and seemed comfortable sharing their experiences, there may have been aspects of their lives that they were not comfortable discussing. These may include such topics as their sexuality, a reluctance to respond to questions about intimate sexual activities, or other areas that may show weakness or other traits that would compromise their masculinity. As a result, there may be certain topic areas that lack some depth.

Contributions of the Research

This research resulted in the informants increasing their self-awareness of their lives and of their disease. The interviews and follow-up summaries encouraged the men to recount their experiences and discuss the various aspects of their illness and how it has affected their lives. Following the interviews, some of the informants expressed a deeper

interest in the arthritis research field and requested certain articles be sent to them. I believe this process has been beneficial for these informants.

This research also has contributed to the field of arthritis, and more specifically the AS literature. This current research has confirmed many of the findings of other arthritis and related chronic disease literature. It has also added new content to the literature in this field by providing a patient experience perspective using a qualitative phenomenological approach which highlighted aspects of living with AS such as the validation of the sick role, shifting masculine roles, and the concern about their futures as fathers that were not previously reported in the literature. As discussed earlier, qualitative research is not common in the field of arthritis or AS and therefore it is helpful to add to that research. This research has uncovered certain aspects of masculinity that are not found in the existing literature and that may be helpful for health promoters and health care providers.

This research may also be applicable to other men and women living with AS. While this research reflects the lived experiences of this group of young men, there are key themes and other findings that may be applicable to a broader AS population. Key themes such as normalcy, control, and work might be applicable to the entire population as these are core tenants of broader western culture. Men and women alike have a desire to be normal, to be in control of their lives and to participate in work; whether it is inside or outside of the home (de Souza & de Lima, 2007). Similarly, the barriers that were found for this population are also applicable to the broader AS population as many people living with chronic disease do not wish to experience side effects from medications or attend medical appointments at times.

Recommendations for Future Research

In this study only one informant had children. This particular informant was open to disclosing his AS to work colleagues, friends and family. Each of these elements was not unique to this informant, yet there was no other man who came forward with such openness. Connell (1995) reports in his research that men must either redouble, reformulate, or reject the hegemonic norms of their culture. Since each of the informants in this research chose to reformulate, I began to wonder if this particular informant had a different experience with this process because he had children. It may be that procreation might be considered the ultimate form of ensuring a person's place as a man. Therefore a future study that explores the experiences of young men with AS who have children would be valuable.

Also because phenomenological inquiry prefers the use of homogenous samples, using other groups of men such as non-Caucasians, older men, those with more severe disease or those who had to leave the workforce would provide additional rich data about AS experiences. Finally, these informants were recruited from the Rheumatology Clinic and therefore, were seeking somewhat regular medical attention. While challenging, it could be important to seek the experiences of those who do not regularly attend clinics.

Knowledge Translation

Following the conclusion of the thesis, I will disseminate the results to various groups and organizations. Specifically, the informants will receive a summary of the final report, if they wish it, as will The Arthritis Society. I will present the findings to the Division of Rheumatology at a team meeting. I will also present the results of this research at the Crossroads Conference, an annual student research conference at

Dalhousie, and a graduate seminar at Dalhousie University.

Summary

This chapter discussed the major themes emerging from the interviews with seven young men with AS and their emphasis on western masculine norms. Young men living with AS see themselves primarily as normal, masculine men which is reflected strongly in their role as provider. The men in this study also expressed a strong connectedness to their sense of independence and control that further enabled them to maintain their masculinity despite the barriers they faced in their daily lives. Applying the Stages of Change Theory highlighted the behaviours of both the informants and their providers that can benefit Health Promoters and other Health Care Professionals, particularly rheumatologists, in the planning of various interventions to assist this population. Finally, the limitations of the research were discussed as well as the overall contribution to the published literature.

Conclusion

This research into the lived experiences of seven young men living with AS has confirmed much of the existing literature in the arthritis and related chronic disease fields, but has also uncovered some perspectives that will be helpful for those living with AS as well as those who care for them. The interpretive phenomenology approach provided a wealth of information-rich data. The importance of masculinity and its strong relationship to the workplace, much like the general masculinity literature, was a key finding in this research providing direction to those who work in the field of rheumatology and other chronic diseases with young men. Health Promoters use of the Stages of Change Theory was further validated in this research, providing a strong basis

for the recommendations for health care providers. The informants expressed a strong need to be seen as normal young men who are in control of their lives, who happen to have a chronic condition. Each man wished to be viewed as a whole person rather than simply someone who is living with AS. Furthermore, the overall need for informational and emotional support among in this study was not pronounced, but rather the informants expressed their independence. Finally, the informants experienced barriers in their daily lives that were both reduced and enabled through their strong sense of masculinity.

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Appendix A - Recruitment Letter

Ankylosing Spondylitis Research Study

Young Adult Volunteers Needed!

Hello! My name is Graeme Kohler and I am a Health Promotion Master's student at Dalhousie University. For my thesis research, I am looking at the experiences of young men with ankylosing spondylitis. My interest in this topic stems from my own family experiences with an older brother with ankylosing spondylitis.

I am currently looking for participants for this study who:

- Are male
- Are currently between the ages of 18-39
- Currently reside in Nova Scotia

If you match these criteria and would like to learn more about participating in the study, please contact me by phone or by e-mail no later than **Friday, April 29, 2011**.

Telephone: ([REDACTED]

E-mail: [REDACTED]

Participation in this study involves two interviews, each approximately 1 hour in length. The interviews will take place at a location that is most convenient for the participant. A small honorarium will be given to study participants to help cover costs associated with participation. I look forward to hearing from you!

Kind regards,

Graeme Kohler, *Principal Investigator*

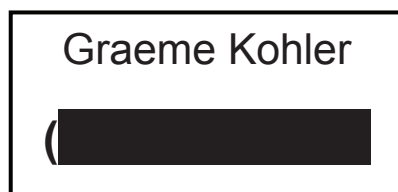
Exploring the Day-to-Day Experiences of Young Men with Ankylosing Spondylitis

Young Adult Volunteers Needed!

As part of my Master's degree at Dalhousie University, I am looking for young adults with **Ankylosing Spondylitis** who:

- Are male
- Are between the ages of 18 and 39
- Currently reside in Nova Scotia
- Have been diagnosed for at least one year

If you match these criteria and would like to learn more about participating in the study, please contact the Principal Investigator, Graeme Kohler, no later than **April 29, 2011**.



Appendix C - Interview Guide

Below is a draft interview guide. I will discuss these particular items with my thesis committee to ensure that I am allowing the informants to discuss their experiences in an open manner. I will begin with broad questions and allow the informant full latitude to describe their experiences of living with AS.

Hi, my name is Graeme Kohler and I am working on completing my Master's thesis in Health Promotion. I want to thank you for meeting with me today. As a part of my thesis, I am conducting research on men who have been diagnosed with ankylosing spondylitis so that I can have a better understanding of what it is like to live with this disease.

Basically, I am interested in hearing your story and anything to do with your life, not just your AS. I have brought some water for you in case you want a drink. I will be tape-recording our session so that I can transcribe it and send it back to you for confirmation of what we talked about. I want to make sure I captured everything correctly.

Demographic

- What is your name?
- What is your age?
- Where do you live?
- Are you married or single/ or living with a partner?
- Do you work?
 - If yes, part time or full time?
 - If part time is this your choice?

- If no, are you on disability?
 - If yes, is it because of your arthritis?
- Do you have children?

Opening

- Please tell me what it is like to live with Ankylosing Spondylitis
- PROMPT: In what ways has AS changed your life?

Physical Health

Tell me about your diagnosis with AS (How long have you had AS?)

- PROMPT: Talk about when you were diagnosed
- PROMPT: Talk about your reaction/ your family's reaction to the diagnosis.
- PROMPT: Talk to me about who diagnosed you and the care you received.

Please tell me about your AS experiences with the health care system

- PROMPT: Tell me about your experiences with the health care professionals you interact with.

PROMPT: Talk about the timeline that you experienced from beginning of symptoms to diagnosis and even up to today (take me through that).

PROMPT: Tell me about your impressions of this process.

Tell me about your knowledge of AS and how you came to learn about it

PROMPT: Talk about the places you went for information (people, web, brochures, TAS)

Please talk about your thoughts on the role genetics played, if any, in your getting AS.

PROMPT: Please discuss any family members that have AS or another type of arthritis and whether you think you “inherited it”.

Please discuss what areas of your life, if any, have changed because of AS?

PROMPT: Consider your work life?

PROMPT: Recreation?

Please tell me about the support you received from the medical community.

PROMPT: What would you say to someone who was newly diagnosed?

PROMPT: In what ways would you improve / change the system?

Please describe how AS has either limited or enabled your life?

Relationships

- Can you tell me about your family life?
 - PROMPT: Talk about your immediate family and their feelings toward your AS
 - PROMPT: Talk about how people in your family found out about your AS
- Do you have children?
- In what way has your diagnosis impacted your decision to have children? Now?
 - How has the information you learned about AS changed your view or experiences about relationships? In what way?

Sexuality

- Please describe how AS has impacted your intimate relationships

PROMPT: What challenges have you experienced sexually because of your disease?

PROMPT: In what ways might your intimate relationships change over time as a result of

AS?

Life Counselling

- Please describe the day you were diagnosed

PROMPT: Can you talk about the interactions you had with health care providers (physicians, nurses, etc.)

PROMPT: Please describe the counselling or advice you received after diagnosis

- Tell me about what things would be helpful for someone who is just diagnosed with AS.
- Talk about the barriers you faced, if any, when you were diagnosed with AS.

Physical Activity

- Tell me about your level of physical activity before diagnosis.
- In what way has your disease changed your physical activity levels?
- In what way have you changed the activities you do?

Psychosocial/Emotional Issues

- Please describe how you felt about being diagnosed with a chronic disease?
- Talk about any fears you may have in light of the fact that you have been diagnosed with AS?

Employment

- Tell me about your experiences with AS at work?
- What concerns you about telling people at work about your AS?

Appendix D - Transcriptionist Contract and Confidentiality Agreement

Confidentiality Agreement

I, _____, understand the sensitive nature of the information I will be transcribing for researcher, Graeme Kohler. I agree to keep all information confidential that I obtain through this process. I will not disclose any identifying information such as names, dates, locations, or other details about the stories I hear on the audiocassette tapes.

When transcribing, I will refrain from using the informant's real name. Instead, I will use the pseudonyms that have been chosen by the informant.

I agree to offer my services for free _____
(initial)

(print name) _____
(date)

(signature)

(Name of researcher) _____
(date)

(Researcher's signature)

Appendix E - Consent Form



Capital Health

Ankylosing Spondylitis Experience Study
Dalhousie University
6230 South Street
Halifax, Nova Scotia
B3H 1V7

CONSENT TO TAKE PART IN A RESEARCH STUDY
Participant Information

“A Qualitative Approach to Understanding the Experiences and Barriers of Young Men with Ankylosing Spondylitis”

PRINCIPAL Investigator: Graeme Kohler

(Master of Arts Candidate (Health Promotion))

Dalhousie University
School of Health & Human Performance
6230 South St
Halifax, Nova Scotia B3H 3J5
Telephone: [REDACTED]

ASSOCIATE Investigators: Please see the attached research team contact page for a full list of the investigators for this study.

PART A.

RESEARCH STUDIES – GENERAL INFORMATION

1. INTRODUCTION

You are invited to join a research study. The study is being offered by Dalhousie University and Capital Health. We are doing this study to find out more about the day-to-day experiences of young men with ankylosing spondylitis. This information will help you decide if you want to be part of the study or not.

2. WHAT WILL I LEARN FROM READING THIS?

In this consent form we will explain why we are doing the study, and what will happen if you decide to take part in the study. We will also tell you about any inconveniences, discomforts or risks that you may experience if you decide to participate in the study.

Please read this carefully. Take as much time as you like. If you like, take it home to think about for a while longer. Mark anything that you don't understand, or wish to have explained in more detail to you. After you have read this consent form, please ask questions about anything that is not clear.

3. WHAT IS A RESEARCH STUDY?

Research studies are ways of finding out new information that can then be used for a particular purpose.

In this study we want to find out more about the experiences of young men with ankylosing spondylitis. We hope that the knowledge gained from this study may be used to assist in the treatment of ankylosing spondylitis and to develop other services for those with AS.

4. DO I HAVE TO TAKE PART IN THIS STUDY?

No! It is completely up to you. Whether you take part or not is for you to decide. You may want to show this to your family, friends, colleagues or family doctor (as you see fit) before you make up your mind. Please feel free to get other opinions at any time.

No matter what you decide, we will support your decision. No one will be upset with you if you decide not to take part or change your mind. Also whether or not you take part in this study will not affect your treatment with your rheumatologist or your family physician. Neither will know whether or not you participate.

If you do decide to take part, you can still change your mind and stop participating at any time.

5. WILL THE STUDY HELP ME?

We do not know. The purpose of the study is to better understand the experiences of young men with ankylosing spondylitis and any barriers they experience in a health care setting, at work, or at home. It is possible that sharing your story with ankylosing spondylitis may personally benefit you by helping you reflect on your experience. Also, we might learn something that will help people with similar problems to yours, or we might not. These things cannot be predicted accurately.

PART B.

EXPLAINING THIS STUDY

6. WHY IS THIS STUDY BEING DONE?

Ankylosing spondylitis affects as many as 4500 Nova Scotians, most of whom are young men. Men often face social pressure to be 'tough' which can lead to additional challenges as they are less likely to see a physician when necessary and report other concerns in their life. Much of the research concerning ankylosing spondylitis is focused on the medical components of the disease such as diagnosis, treatment, and management. There is a clear need for additional research exploring the experiences of young men with ankylosing spondylitis so that other life challenges and successes can be reported. By improving the knowledge base in this area, it is possible to impact future treatment and programming for young men with ankylosing spondylitis.

7. WHY AM I BEING ASKED TO JOIN THE STUDY?

You are being asked to join the study because you are a young adult male with ankylosing spondylitis and you contacted us after seeing our advertisement and expressed interest in the study.

8. WHO CAN TAKE PART IN THIS STUDY?

You may take part in this study if the answer is YES to all of the following:

- ✓ You are male;
- ✓ You have been diagnosed with ankylosing spondylitis;
- ✓ You are currently between the ages of eighteen (18) and thirty-nine (39);
- ✓ You have been diagnosed with ankylosing spondylitis for at least one (1) year;
- ✓ You are willing to take part in the study, including signing this form after carefully reading it.

BUT, if the answer to any of the following is YES, you will NOT be able to take part in this study:

- ∅ You are currently younger than eighteen (18) years old;
- ∅ You are currently older than thirty-nine (39) years old;
- ∅ You have been diagnosed with ankylosing spondylitis for less than one (1) year;
- ∅ You have serious social, mental or medical conditions that would stop you taking
 - ∅ part in the study properly (For example, participating in an interview that lasts one and a half (1.5) hours).

All of these will be discussed in more detail with you. You will also be told the reasons they are important.

9. HOW LONG WILL I BE IN THE STUDY?

Overall, this study will take about three (3) hours and forty-five (45) minutes of your time. There are two interviews. The first one will take approximately one (1) hour. The second interview will take between forty-five (45) minutes and one (1) hour. In addition to the interviews, approximately one (1) hour and forty-five (45) minutes of your time is required for the following: 1) Getting familiar with the study and your role in it (For example, reviewing this informed consent form); 2) Communicating with the Principal Investigator to set up dates, times, and locations for interviews; 3) Possible travel to and from the interview; and 4) Reviewing summaries of your two (2) interviews to make sure that they are an accurate reflection of your thoughts and opinions.

Participation in this study will take place over a five (5) to six (6) week period. The first interview will take place one (1) to two (2) weeks following the initial conversation between the Principal Investigator and the potential participant. The second interview will take place four (4) weeks after the first interview.

Finally, the results of this study will be available approximately six (6) months after your

participation. If you would like to receive a copy of the results of this study, please check the appropriate box on the consent form.

10. HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

Between ten (10) and fifteen (15) participants will be recruited for the study. The exact number of participants will be determined by participant availability. The purpose of this study is to identify the common experiences shared by young men with ankylosing spondylitis. If no new themes are coming out after interviews with ten (10) participants, and no new men volunteer to participate, recruitment will end and there will be ten (10) participants in the study. However, if new themes are still being identified after ten (10) interviews, we will continue to recruit more participants so that we can make sure that we have an in-depth understanding of the experiences of young men with ankylosing spondylitis. We will not take more than fifteen (15) participants based on the time limitations associated with this Master's level study.

It is expected that all of the participants will come from Nova Scotia. We will not accept participants from outside of Nova Scotia based on travel limitations.

11. HOW IS THE STUDY BEING DONE?

This study will consist of one in-depth interview and a second follow-up interview with each participant. All interviews will be audiotape recorded and transcribed. The first interview will last approximately one (1) hour and will explore questions regarding participant experience of being diagnosed with ankylosing spondylitis, and how this experience has affected his life.

Within a couple weeks of the first interview, the participant will receive a summary of the main themes identified in his interview and asked to reflect on them. A second interview will be scheduled to take place approximately four (4) weeks after the participant receives this summary. The second interview will last approximately one (1) hour, and will provide an opportunity to verify and clarify issues arising from the first interview.

After all the interviews are complete, we (my supervisor and me) will analyze the data to see what similarities and differences exist among the experiences of all the participants. We will try to identify the specific thoughts, feelings, and attitudes that are shared by the participants so that we can paint a collective picture of what it is like to be a young man with ankylosing spondylitis.

The findings from this research study will be shared with The Arthritis Society and the CDHA Rheumatology department. Also, an easy-to-read summary of the research will be created and made available to participants. Finally, we will submit articles based on

this research to health-related journals so that doctors, nurses, and other health-related professionals can learn about the young adult perspective on ankylosing spondylitis. Hopefully, this will contribute to the quality of care received by men with ankylosing spondylitis and to the development of educational resources and supportive programs and services.

To protect the privacy of the participants, all identifying information such as names and locations will be removed before sharing the findings. Before signing the Informed Consent form, participants will be asked if they are comfortable with the researchers using direct quotes from their interviews. If they give their permission, they will have a chance to view the selected quotes before they are used in reports or publications. Participants will be mailed a copy of the document, and can decide to modify or withdraw their comment if they think they have been misquoted, or are simply not comfortable with their exact words being used in a report or publication. Participants will be reminded that names and any other identifiers will be removed or replaced with pseudonyms (fake names) to protect their identity.

12. WHAT WILL HAPPEN IF I TAKE PART IN THIS STUDY?

Here are the steps we will follow after you contact us about participating in the study:

1. INITIAL SCREENING

The Principal Investigator will have an initial conversation with you over the phone or through e-mail (depending on your preference). He will give you some more details on the study and then he will ask you some questions to find out whether you match the eligibility criteria for this study (e.g., male between the ages of eighteen (18) and thirty-nine (39)). If you match the criteria, and you are still interested in participating, he will mail you a copy of this Informed Consent form and a copy of the Interview Guide. A date, time, and location for the first interview will be scheduled based on what is most convenient for you.

Estimated Time: approximately thirty (30) minutes

2. REVIEW OF INFORMED CONSENT AND INTERVIEW GUIDE

Upon receiving this Informed Consent form and the Interview Guide through the mail, you are asked to review these documents to help you learn more about the study and to help you feel prepared for the upcoming interview. Please feel free to show these documents to your family, friends, colleagues, or a family doctor if you would like to get other opinions. You are also encouraged to contact the Principal Investigator at any time if you have any questions or concerns about the study. His contact information is on the first page of this form.

Estimated Time: approximately thirty (30) minutes

3. INTERVIEW #1

Before starting the first interview, the Principal Investigator will orally review this Informed Consent form with you and provide you with an opportunity to ask any questions you may have. If you are comfortable with your decision to participate in the study, you will be asked to sign this form and the interview will begin. The interview will mainly consist of the questions listed in the Interview Guide. Based on your answers, the Principal Investigator may also ask you some questions to help clarify his understanding of what you saying, or to add more detail to your response.

Estimated Time: approximately one (1) hour

4. BETWEEN INTERVIEWS

About four (4) weeks after the first interview, you will receive a written summary of the main themes identified from that interview. You will be asked to check it over to see if these themes are an accurate reflection of your experience.

Estimated Time: approximately fifteen (15) minutes

5. SECOND INTERVIEW

A second follow-up interview will be scheduled approximately one (1) month after the first interview. The purpose of this second interview is to allow you an opportunity to clarify any of the responses you gave during the first interview and/or to add anything new that you think would be valuable to the research.

Estimated Time: approximately one (1) hour

6. ADDITIONAL TIME

Additional time may be required for you to travel to the interview location. Both interviews will take place in a location agreed upon by the participant and the researcher, and in a location that provides comfort and privacy.

Estimated Time: approximately thirty (30) minutes

In total, your participation in this study is expected to take approximately three (3) hours and forty-five (45) minutes. This time commitment will take place over the course of five (5) to six (6) weeks.

13. ARE THERE RISKS TO THE STUDY?

There are risks with this, or any study. To give you the most complete information available, we have listed many *possible* risks, which may appear alarming. We do not want to alarm you but we do want to make sure that if you decide to try the study, you have had

a chance to think about the risks carefully. Please be aware that there may be risks that we don't yet know about.

INTERVIEWS

You may find the interviews upsetting or distressing. You may not like all of the questions that you will be asked. You do not have to answer those questions you find distressing.

PRIVACY & CONFIDENTIALITY

The Informed Consent form and the original audiotape recordings of your interview will contain your name as well as other information about you. However, these forms and recordings will not be shared with anyone other than the Principal Investigator. If you look on the Research Team Contact Page, you will see that there are three (3) Associate Investigators in this study. One (1) of them is a professor at Dalhousie University and one (1) is a doctor who works at Capital Health. The other one (1) is a professor at Dalhousie who is the thesis supervisor of the Principal Investigator. Because there is a chance that you may know the doctor, your personal information will not be shared with him. Although he would never share your information with anyone or change the care he may provide to you based on your participation in this study, we want to take all steps to ensure that you feel comfortable participating in this study.

Every effort will be made to safeguard your privacy, including the removal of all identifying information from study reports and publications. However, there is still a chance that individuals may be able to identify you when they read the report or publication. They may approach you about your experience with ankylosing spondylitis or tell other people about the report or publication. This may make you feel uncomfortable or distressed. However, we think the chance of this ever happening to you is very small.

14. WHAT ARE MY RESPONSIBILITIES?

As a study participant you will be expected to:

- follow the directions of the Principal Investigator
- contribute three (3) hours and forty-five (45) minutes of your time to the study

15. CAN I BE TAKEN OUT OF THE STUDY WITHOUT MY CONSENT?

Yes. You may be taken out of the study at any time, if:

- There is new information that shows that being in this study is not in your best interests.
- The Capital Health Research Ethics Board or the Principal Investigator decides to stop the study.

You will be told about the reasons you might need to be taken out of the study.

16. WHAT ABOUT NEW INFORMATION?

It is possible (but unlikely) that new information may become available while you are in the study that might affect your health or willingness to stay in the study. If this happens, you will be informed in a timely manner and will be asked whether you wish to continue taking part in the study or not.

17. WILL IT COST ME ANYTHING?

Compensation

You will receive an honorarium of fifteen dollars (\$15) for your participation. You will receive fifteen (\$15) after the first interview. This money is intended to cover any expenses related to your participation, such as travel and parking, and to serve as a gesture of appreciation for donating your time to participate in this study.

18. WHAT ABOUT MY RIGHT TO PRIVACY?

We will do everything possible to keep your personal information confidential. Although your name may be used in the study records, no identifying information (such as your name) will be sent outside of Capital Health and Dalhousie University. Instead we will use a pseudonym (a fake name) on any information sent outside of Capital Health and Dalhousie University (e.g., a study report). If the results of this study are presented at a meeting, or published, nobody will be able to tell that you were in the study.

Your records will be stored in a secure area such as a locked file cabinet in the supervisor's office during the study, and after the study ends they will be kept for 7 years in a secure storage area. The storage area will be on the campus of Dalhousie University.

Some other people or groups may need to check or see your study records to make sure all of the information is correct. All of these people have a professional responsibility to protect your privacy.

These groups and people are:

- The Capital District Health Authority Research Ethics Board (CHREB) which is responsible for the protection of people in research here
- Quality assurance staff including the auditors for the CHREB, who ensure that the study is being conducted properly

- The Dalhousie University Health Sciences Human Research Ethics Board (DUHSREB), which is responsible for the protection of people involved in studies conducted through their university

The information they check may include the audio-recordings of the interviews as well as the interview transcripts. If you have been diagnosed with ankylosing spondylitis, the researchers and people or groups listed above may access your health records to verify the ankylosing spondylitis diagnosis only.

If you decide to withdraw your consent, your health records will be made available as described above (up to the date you withdrew your consent) for the duration of the study.

You may also be contacted personally by the Capital Health or Dalhousie University research auditors for quality assurance purposes.

You may ask the Principal Investigator to see and copy your personal information related to the study. You may also ask the Principal Investigator to correct any study related information about you that is wrong.

19. WHAT IF I WANT TO QUIT THE STUDY?

If you chose to participate and later change your mind, you can say no and stop the research at any time. If you wish to withdraw your consent, please inform the Principal Investigator. All data collected up to the date you withdraw your consent will remain in the study records, and may be included in study related analyses.

20. DECLARATION OF FINANCIAL INTEREST

The Principal Investigator has no financial interests in conducting this research study.

21. WHAT ABOUT QUESTIONS OR PROBLEMS?

For further information about the study call **Graeme Kohler**. Mr. Kohler is in charge of this study at this institution (he is the “Principal Investigator”). Mr. Kohler’s telephone number is (██████████). If you can’t reach the Principal Investigator, please refer to the attached Research Team Contact Page for a full list of the people you can contact for further information about the study.

The Principal Investigator is **Graeme Kohler**
Telephone: (██████████)

22. WHAT ARE MY RIGHTS?

After you have signed this consent form you will be given a copy.

If you have any questions about your rights as a research participant, contact the **Patient Representative** at **(902) 473-2133**.

In the next part you will be asked if you agree (consent) to join this study. If the answer is “yes”, you will need to sign the form.

Research Team Contact Information

Principal Investigator: Graeme Kohler
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Associate Investigator: Dr. Fred McGinn
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Room 245 Nova Scotia Rehabilitation Centre
1341 Summer St.
Halifax, Nova Scotia, B3H 2Y9
Telephone: (██████████)

PART C.

23. CONSENT FORM AND SIGNATURES

I have reviewed all of the information in this consent form related to the study called:

“A Qualitative Approach to Understanding the Experiences and Barriers of Young Men with Ankylosing Spondylitis”

I have been given the opportunity to discuss this study. All of my questions have been answered to my satisfaction.

I agree to allow the people described in this consent form to have access to my health records.

This signature on this consent form means that I agree to take part in this study. I understand that I am free to withdraw at any time.

*** OPTIONAL ***

- I consent to the use of direct quotations from my interviews to be used in reports relating to this study so long as my name and other identifying information are not used
- I consent to be audio-taped recorded
- I would like to receive a copy of the results of this study

Signature of Participant Name (Printed) Year / Month / Day*

Witness to Participant’s Signature Name (Printed) Year / Month / Day*

Signature of Investigator Name (Printed) Year / Month / Day*

Signature of Person Conducting *Name (Printed)* *Year / Month / Day**
Consent Discussion

****Note: Please fill in the dates personally***
I will be given a signed copy of this consent form

Thank you for your time and patience!

Appendix F - Honorarium Receipt

Receipt	
I,	

_____, hereby confirm that I have	
received a sum	
<i>Participant's Name (Printed)</i>	
of	\$ _____ from

as an honorarium	
<i>Principal</i>	
<i>Investigator's Name (Printed)</i>	