

QUALITY OF LIFE

NATIONAL REPORT
2020

Canadian Spondylitis Association



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EXECUTIVE SUMMARY

Overview

Spondyloarthritis (SpA), also referred to as spondylitis or spondyloarthropathies, is an umbrella term used to describe a group of chronic inflammatory arthritic conditions with common features including inflammation of the spine, eyes, skin, and gastrointestinal tract. This group of conditions is clinically and genetically related but has distinct entities with several genetic, prognostic, and therapeutic differences. To date, it is estimated that approximately 430,000 - 860,000 (1-2%) Canadians have been diagnosed with a Spondyloarthritic condition.

The journey people go through with SpA is onerous and can majorly impact quality of life. For many, these conditions are very painful and debilitating, particularly for those in which the disease has progressed. For some, it takes a very long time to receive a diagnosis, while others live with a misdiagnosis for many years. On average, diagnosis of these conditions can take up to 7 years or longer. For women, it's not uncommon to take 2 additional years to receive a diagnosis. People who are diagnosed earlier and are put onto medications sooner are positioned to do better than those who have disease progression. However, the journey to controlling SpA often involves being prescribed treatments and failing on several different medications before finding one that is effective. Similarly, delayed diagnosis and treatment can lead to irreversible damage to the spine and other joints.

SpA affects children, women, and men worldwide, with the onset of symptoms experienced in early childhood and expanding throughout one's lifespan. While many treatment options exist for individuals living with SpA, little is known about the causes of SpA and there is no cure. SpA impacts every aspect of an individual's life, including their ability to work and maintain social and intimate relationships. In addition to the tremendous medical burden, the psychological impact of searching for a diagnosis and trying to find a medication that controls the disease is significant. Many individuals suffer from depression, anxiety, and low self-confidence, as well as fatigue and sleep deprivation.

The objectives of the **Quality of Life Survey** that the CSA launched in November of 2019 and closed in January 2020 were to elicit a stronger understanding of the patient journey and impact on those living with various forms of Spondyloarthritis. The survey examined patient demographics, SpA diagnosis and management, employment, quality of life, health and wellness, treatment and medications, and complications associated with SpA. In addition, the survey objective was to validate that while every patient's journey is unique, there are shared experiences across individuals living with SpA.

KEY FINDINGS

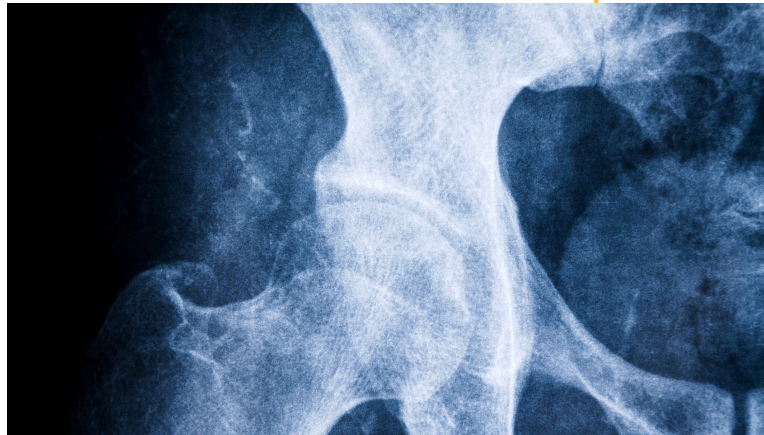
The following section outlines the key findings from the Quality of Life Survey:

66% of respondents had been diagnosed with Ankylosing Spondylitis and 24% with Psoriatic Arthritis. 22% were diagnosed with more than one form of SpA.

Over 70% reported their day-to-day life was negatively impacted by SpA. Only 7% indicated no impact on their daily life and 22% said it was somewhat impacted. Ability to remain in the workplace was impacted and 16% reported being on long-term disability and 4% on short-term disability. There were 7% who retired early due to their disease.

Sleep loss/interruption was reported by 89% and 74% said they avoid social events. 41% of participants were highly restricted by SpA when it came to tasks like outdoor yard work. Other highly restricted tasks included exercise (36%) and cleaning (31%). Tasks of medium restriction included preparing meals (31%) and engaging in intimate relations (30%).

Upon diagnosis and disease progression, many reported less frequent participation in exercise, travel, intimate relationships, social outings, and family activities. Some even said they stopped participating in these altogether.



KEY FINDINGS (continued)



When asked to rank what was most important regarding QOL, most ranked living with no/reduced pain as most important, followed by improved sleep/no fatigue. The least important were returning to work and going out with friends.

In total, participants had an average of 3.3 complications. Those living with ankylosing spondylitis experienced an average of 3.5 complications while those with psoriatic arthritis reported an average of 3.9.



Sleep issues (65%), chronic pain (63%), and combined depression and anxiety (56%) were the most prevalent conditions reported among participants. In addition, 23% said they live with inflammatory bowel disease. Other complications included uveitis, weight issues, migraine, vertebral disc herniations, and hypertension.

Those who reported weight issues (over 44%) consequently had increased anxiety, depression, and chronic pain compared to those without weight issues.



Over 65% reported experiencing sleep issues. Many (26%) said that nothing helps with their sleep. Others used cannabis (24%), prescribed sleeping pills (20%), and exercise (19%) to cope.

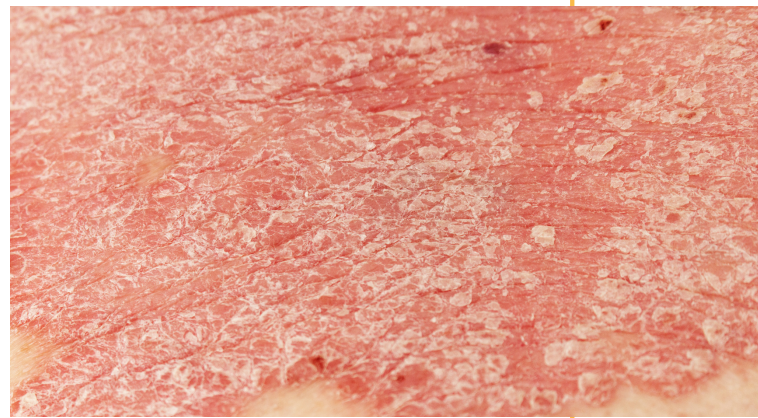
KEY FINDINGS

(continued)

36% of participants said that they suffer from chronic fatigue syndrome. When asked how they manage their fatigue, the most common answer was exercise. Most participants said they have yet to find something that helps them efficiently manage their fatigue.

Over 400 people said they suffer from either depression or anxiety, or both. When asked how they cope with this, 40% said talking to loved ones. Exercise to cope was reported by 32% and 31% take prescription medication. Those who suffer from Psoriasis experienced a higher prevalence of anxiety and depression.

The survey results validate the significant and varied impact SpA has on patients' quality of life and conclude that greater awareness of symptoms, earlier diagnosis, and treatment interventions are critical to improving outcomes and the quality of life of Canadians living with chronic diseases like spondyloarthritis. From the results, the following recommendations have been identified and will guide the CSA initiatives to support Canadians living with Spondyloarthritis.



ABOUT US

The Canadian Spondylitis Association (CSA) is a federally registered not-for-profit organization. It is the first and only patient-led organization developed for and solely focused on supporting Canadians living with Spondyloarthritis. The CSA plays an essential role in helping individuals diagnosed with and affected by Spondyloarthritis achieve their full health potential and improve their quality of life. The mission of the CSA is to be the leading voice for the Spondyloarthritis community in Canada, raising awareness and providing support, education, and advocacy for patients, caregivers, and healthcare professionals. Its vision is that all of those living with, or affected by, Spondyloarthritis receive timely diagnosis and treatment, make informed choices about their well-being, and are supported by a thriving Spondyloarthritis community.



BACKGROUND

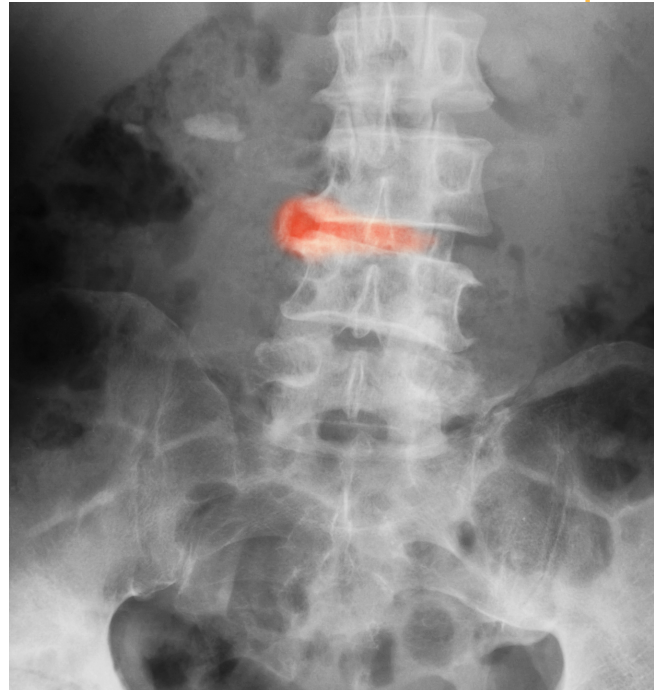
WHAT IS SPONDYLOARTHRITIS?

The term spondyloarthritis (SpA) describes a group of chronic inflammatory arthritic diseases with common features including inflammation of the spine, eyes, skin, and gastrointestinal tract. This group, sometimes referred to as spondylitis and spondyloarthropathies, is clinically and genetically related, but has distinct entities with several genetic, prognostic, and therapeutic differences. SpA can be broken down into two subsets, axial spondyloarthritis (AxSpA) and peripheral spondyloarthritis (pSpA). AxSpA affects the spine and sacroiliac joints (the joints between the pelvis and the sacrum or base of the spine), while pSpA affects areas away from the spine and sacroiliac joint, such as finger, arm, foot, and leg joints, as well as the insertion of muscles and ligaments into bones (entheses).

CHARACTERISTICS OF SPONDYLOARTHRITIS

While the experience with SpA differs from person to person, there are some common characteristics across spondyloarthritic conditions:

- Spinal arthritis
- Peripheral arthritis that differs from rheumatoid arthritis
- The presence of the HLA-B27 gene
- People with SpA do not have rheumatoid factor antibodies in their blood (as commonly seen in individuals with rheumatoid arthritis). They are seronegative, whereas people with rheumatoid arthritis are seropositive.
- Extra articular manifestations of inflammatory bowel disease (IBD), psoriatic arthritis (PsA), and uveitis.



WHAT CAUSES SPONDYLOARTHRITIS?

We don't know what causes SpA, but we do know that there is a genetic factor. About 90% of people with SpA carry the HLA-B27 gene, a gene that is found in about 7% of the White Western European population. The involvement of this gene has been known since 1973 but there is no defining mechanism known by which B27 causes SpA. Confusingly, the other 10% of people with SpA do not have the HLA-B27 gene, so there must be other factors at play. Researchers have now identified at least twenty genes that have been linked to SpA but their role is not well understood. A great deal of genetic research is going on worldwide to identify the genes associated with SpA and the susceptibility of someone with these genes developing the disease.

BACKGROUND

(continued)

WHO GETS SPONDYLOARTHRITIS?

Although it is estimated that SpA affects the same amount of people as rheumatoid arthritis, which is nearly 1-2% of Canadians, there is very little general knowledge about spondyloarthritic conditions. We know that people with a family member with spondyloarthritis are at higher risk of developing SpA depending on whether they inherited the HLA-B27 gene (about 90% of people who develop spondyloarthritis will carry the HLA-B27 gene). We also know that SpA affects both men and women, often starting in the teen years and early twenties with the onset of symptoms occurring in early childhood and expanding throughout one's lifespan. It is unusual for SpA to start after age 45 but not uncommon for people to not get diagnosed until they are in their 40's or 50's. Lastly, we know that SpA predominantly affects White Western European populations (the HLA-B27 gene can be found in approximately 7% of this population), with lower rates in other ethnic groups.

LIVING WITH SPONDYLOARTHRITIS

Individuals who are able to manage and control their condition can live fairly normal lives. However, many people with SpA suffer great loss in their lives due to their relentless and unmanageable condition(s). For many, these conditions are painful and debilitating, and a significant number of people live in isolation and desperation due to SpA. Some individuals are even forced to leave their jobs and lose important relationships. In addition to the physical and mental burden of SpA itself, having one or more spondyloarthritic conditions may increase the risk of developing other conditions including chronic pain, depression, anxiety, psoriasis, Crohn's disease, and cardiovascular or lung issues.

The Canadian Spondylitis Association

launched this survey to better understand how the quality of life of individuals is impacted by spondyloarthritic conditions. The findings and insights learned will influence the future work conducted by the CSA to improve the lives of people living with SpA.

This report will provide a baseline comparison as we move forward and track the progress of our healthcare system in accessing healthcare professionals, medications, services, and supports. It will also track our efforts to reduce the time to diagnosis and improve outcomes.



METHODS

The **Canadian Spondylitis Association** developed an online **Quality of Life Survey** for Spondyloarthritis patients. The survey was reviewed and tested from a patient perspective for clarity, comprehensiveness, and what resonates with individuals who live with various forms of spondyloarthritis.

SURVEY ELIGIBILITY CRITERIA: The criteria to participate in the survey was to have a diagnosis of one or more spondyloarthritic conditions.

The survey was created in Survey Monkey and designed to be completed within 20-25 minutes. The average length taken to complete the survey was 22 minutes.

SURVEY DISSEMINATION:

The survey was disseminated electronically by the CSA through various social media platforms (Facebook, Twitter, Instagram, Mail Chimp, and the CSA website) to access a national cross-section of participants. It was also disseminated by the Canadian Association of Psoriasis Patients, the Canadian Psoriasis Network, and the Canadian Arthritis Patient Alliance.

Respondents were encouraged to share the link with others in their community who may be interested in sharing their experiences and having their voices heard. **The Quality of Life Survey** was open from November 20, 2019 to January 31, 2020. During this time, 838 people responded to the survey.



RESULTS

Introduction to the Results

The Canadian Spondylitis Association surveyed members of the Spondyloarthritic community from November 20th, 2019 to January 31st, 2020. During this time, 838 people responded to the survey. Since not every question was mandatory during the survey, the number of participants per section varies. In order to accurately describe the responses, we will note how many people responded at the beginning of each section.

Additionally, participants were divided into groups to further understand the impact of disease on individuals. Group A was composed of those living with Axial Spondylitis (axSpA), including Ankylosing Spondylitis as well as radiographic and non-radiographic axSpA. Group B included those living with Peripheral Spondylitis, including Psoriatic Arthritis. During the discussion, these groups will be referred to as Group A and Group B.

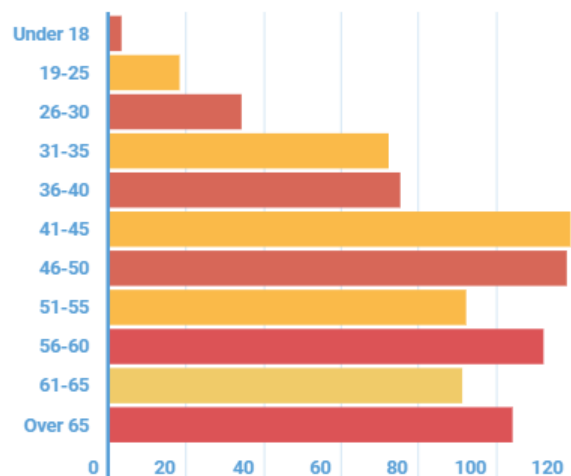
GETTING TO KNOW YOU

This section was completed by 838 participants.

Of these participants, 615 (74%) identified as female. 213 identified as male, 2 identified as transgender, 2 did not identify with a gender, and 6 preferred not to answer. The age demographic ranged from under 18 to above 65, with most participants falling between the ages of 41 and 50.



Figure 1: Age Demographic

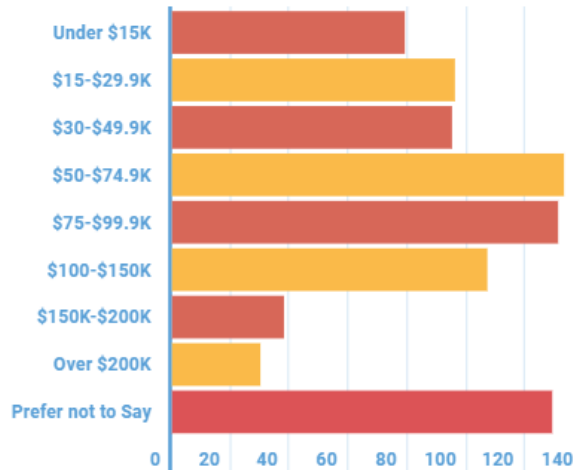


RESULTS

(Getting to Know You - continued)

People from all of the Canadian provinces and territories, with the exception of Nunavut, responded to the survey. 34% of the participants lived in Ontario, 15% were from Manitoba, 14% from Alberta, and 8% from Quebec. In the other category, participants identified many other countries such as the United States of America, Ireland, South Africa, and the United Kingdom. The respondents were asked to identify their household income in order for us to evaluate the economic burden of Spondyloarthritis on an individual. 16% reported a household income between \$50-\$75K and 75-\$100K. 13% had a household income between \$100K-\$150K.

Figure 2: Household Income



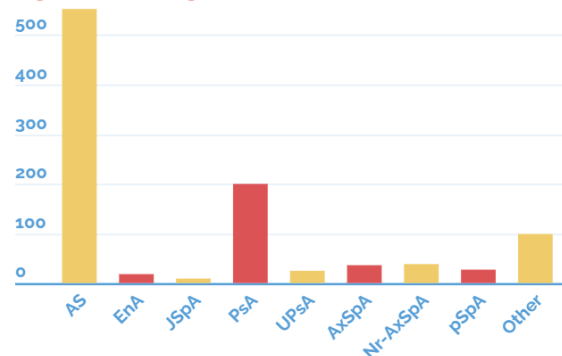
DIAGNOSIS & MANAGEMENT

This section was filled out by 706 people, with the exception of the diagnosis question, which was answered by 838.

Most respondents (66%) indicated that they had been diagnosed with Ankylosing Spondylitis and 24% had been diagnosed with Psoriatic Arthritis. In the comments section, people indicated that they had been diagnosed with other diseases such as inflammatory bowel disease, fibromyalgia, osteoarthritis, or a combination of diseases. Some also said that they have been suffering for years but still do not have a definite diagnosis. 31% indicated that they had been diagnosed with a complication of a SpA disease prior to their SpA diagnosis. 38% were diagnosed with their SpA condition first and 31% were unsure.

“It took a long time to be diagnosed. Doctors either didn’t believe me about my pain, or think I was looking for meds at the ER. They tried to say I was making it all up. I was not taken seriously. I could have been diagnosed and treated years ago.”

Figure 3: Diagnosis



Abbreviations

- AS = Ankylosing Spondylitis
- EnA = Enteropathic Arthritis
- JSpA = Juvenile Spondyloarthritis
- PsA = Psoriatic Arthritis
- USpA = Undifferentiated Spondyloarthritis
- AxSpA = Axial Spondyloarthritis
- Nr-AxSpa = Non-radiographic axial spondyloarthritis
- pSpA = Peripheral Spondyloarthritis

RESULTS

(Diagnosis & Management - continued)

When asked who diagnosed their SpA condition, 81% said it was a rheumatologist, 9% had been diagnosed by a family doctor, and less than 2% had been diagnosed by a dermatologist, gastroenterologist, internist, ER doctor, or ophthalmologist. In the provided comments section, other participants indicated that they had been diagnosed by a neurologist, radiologist, chiropractor, or orthopedic surgeon. Upon further questioning, it was revealed that prior to their diagnosis, 37% had been told by a family physician that they suspected a spondyloarthritic condition. Other healthcare professionals that suggested someone may have a SpA condition include physiotherapists, chiropractors, and dermatologists, as well as other people living with SpA.

Most participants (39%) had been diagnosed with their condition for 1-5 years. 14% had been diagnosed for less than 1 year, 16% between 6 and 10 years, 11% for 11 to 15 years, 6% for 15 to 20 years, and 15% have been diagnosed for over 20 years. Additionally, most people lived with symptoms for 1-5 years before receiving their diagnosis. The mean age of diagnosis among our participants was 38 years old.

“It took me years to get diagnosed. It’s like no one believes you when you are telling them about symptoms. For a while I just gave up and suffered until things were so bad [I] couldn’t deal with it any longer and went to a different doctor.”

22% of the participants have been diagnosed with more than one form of SpA. Of those with multiple SpA conditions, 33% were diagnosed within 1 to 5 years of their first diagnosis. 24% were diagnosed within one year, 10.8% between 6 and 10 years, 4% between 11 and 15 years, 3% between 16 and 20 years, and 7% were diagnosed 20 or more years later. 18% of those with multiple forms of SpA had their conditions diagnosed at the same time.

Figure 4: Years lived with Symptoms Prior to diagnosis

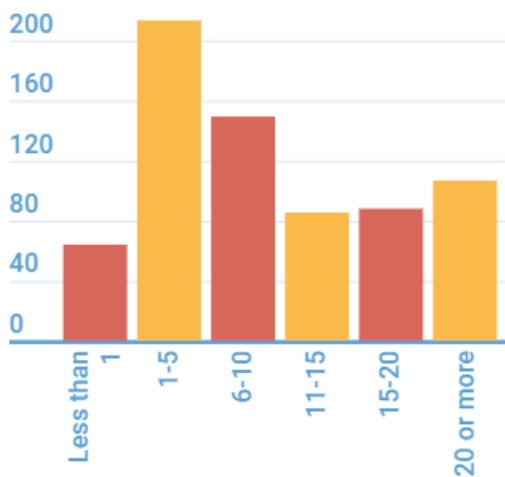
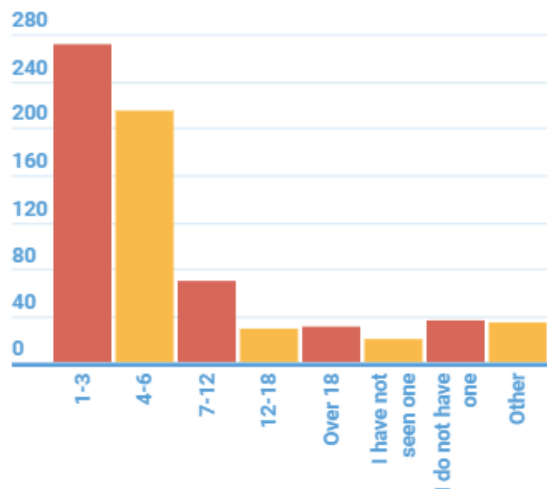


Figure 5: Wait time to see a Rheumatologist (in Months)



RESULTS

(Diagnosis & Management - continued)

When asked about the wait time to see a rheumatologist, the majority of participants (38%) reported waiting 1 to 3 months, while 30% of participants waited 4 to 6 months and 10% waited 7 to 12 months. Alternatively, 5% said that they do not have a rheumatologist and 3% have not seen a rheumatologist.

Of the 609 participants who see a rheumatologist, most (76%) have 2 or more appointments per year. 19% see their rheumatologist once per year, and 6% do not see their rheumatologist on a yearly basis. In the comments section, some indicated that they see their rheumatologist regularly, such as every 6 months, and others said they only make appointments when needed

Most people (56%) indicated that they travel under 25 km to see their rheumatologist/treating physician. In addition, 69% said they drive themselves to their appointments. 24% are driven by a friend or family member, 12% use public transportation, 6% take a taxi or Uber, and 4% walk to their appointments. Of the 5% who answered "other" to this question, some said that they use air travel, some rent a car, and others bike.

Figure 6: One-way travel Time to Rheumatologist/Treating physician

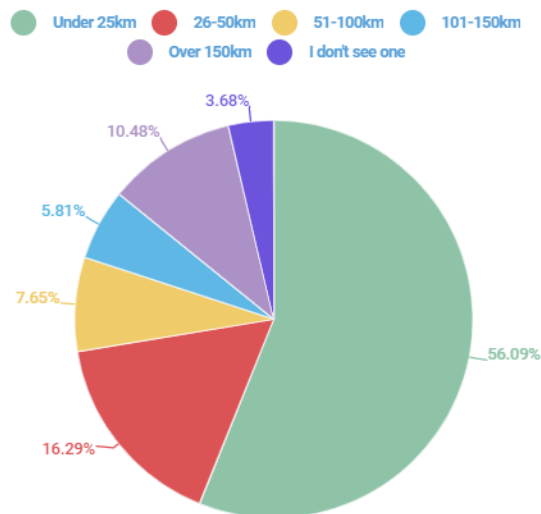
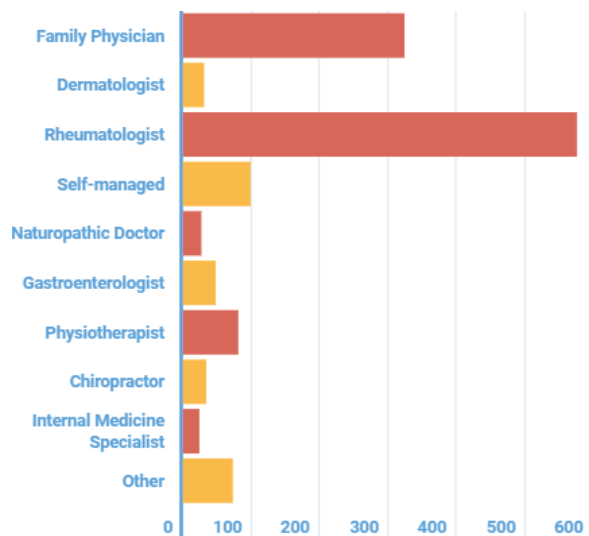


Figure 7: Primary Healthcare Professional(s) Managing the Treatment of SpA Conditions



The majority of participants (82%) indicated that their rheumatologist is the primary healthcare provider who manages the treatment of their condition. When responding to this question, participants could identify more than one answer. 46% indicated that their family physician manages their treatment and 14% were self managed. In the other section, healthcare professionals such as pain specialists, massage therapists, nutritionists, and ophthalmologists were identified. The average number of primary healthcare providers per survey respondent was 1.57.

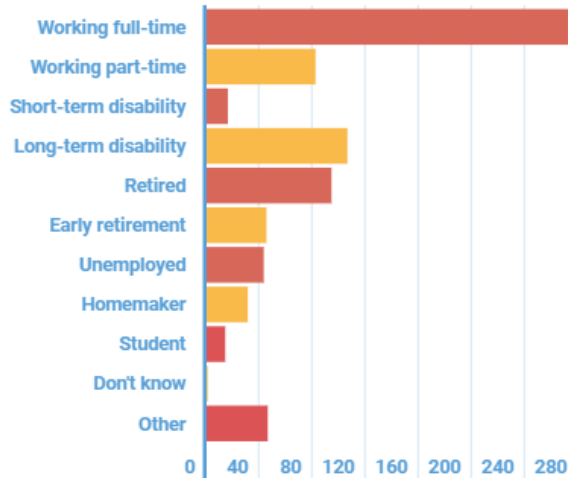
RESULTS

EMPLOYMENT/WORKPLACE

This section was completed by 669 participants.

41% said that they were working full-time, including self-employment. 2% were on short-term disability and 16% were on long-term disability. In the comments section, many participants expressed that they had to reduce the hours they worked or quit their jobs entirely due to pain and discomfort caused by the condition. Some indicated that they were currently unemployed due to SpA and awaiting acceptance for disability and others did occasional contract work.

Figure 8 : Current Employment Status



40.0% of participants in Group A were working full time, compared to 31.7% in Group B. 17.9% of Group A was either on short- or long-term disability, compared to 16.4% of Group B. 6.8% of Group A had retired early due to their illness, compared to 7.7% of Group B.

Of the 392 participants who indicated that they work, 39.5% work between 31 and 40 hours per week. 5.6% work less than 10 hours per week, 8.9% work 11-20 hours per week, 7.4% work 21-25 hours per week, 7.9% work 26-30 hours per week, and 25% work 41 to 50 hours per week. 5.6% said they worked over 50 hours per week.

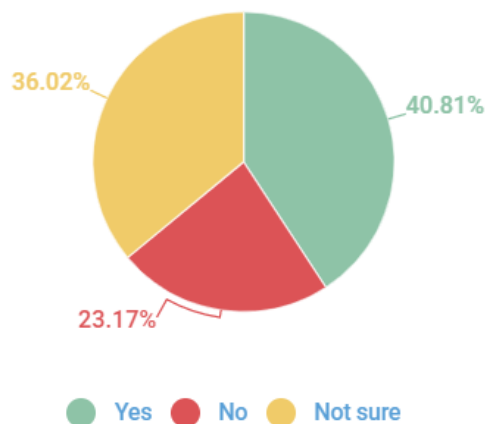
Note:

Group A = Responders diagnosed with AS or axSpA or nr-axSpA

Group B = Responders diagnosed with PSpA or PsA

76% of employees said that they disclosed their illness to their employer. 56% of people who disclosed their condition said they did so upon diagnosis, but they had already been employed. 31% said they disclosed after they had been working there for a while and 13% disclosed at the time of being hired. 41% of participants said they feel their workplace would accommodate their condition by various methods such as ergonomic assessments, adjusting the type of tasks performed, and work scheduling. However, the majority of participants surveyed did not feel that their workplace would be accommodating or were unsure.

Figure 9: Do you feel your workplace would be Open to Accomodating your condition?



RESULTS

(Employment / Workplace - continued)

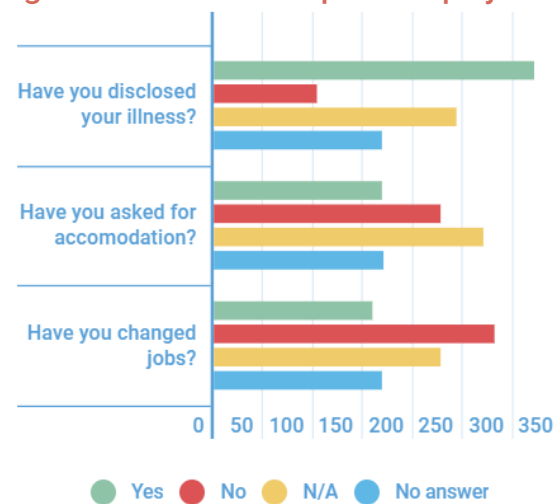
25% of working participants said that they have asked for accommodation at their workplace and were accommodated in some way. These accommodations included standing desks, flexible work hours, tele-work during periods of flares, and ergonomic assessments. However, the majority of participants expressed difficulty or denial of their requests for accommodations from their employer, either due to the cost of the required materials or general lack of understanding surrounding SpA and chronic pain. Others also stated that they would lose their job if they asked for accommodations.

“I had to get medical doctors orders for any accommodation. Did not accommodate me without and pressured me “when am I going to get better” when trying to find the correct biologic for me and I was in much physical and emotional turmoil.”

“My employer chose to not believe me that I was sick, even though I presented medical notes. I was forced out of my job due to illness. I have sought out therapy to heal with the abuse I suffered in my workplace.”

36% of participants in the workforce said that they have changed their type of work due to their SpA condition. For example, one person used to work as a clinical nurse but now works as a healthcare manager since it requires less physical work and has regular hours, rather than shift work. Many people also indicated they used to have high-stress jobs and switched to a different position, within the same field, in order to have less stress. Switching to remote work and ceasing to work were also common answers.

Figure 10: The Effect of SpA on Employment



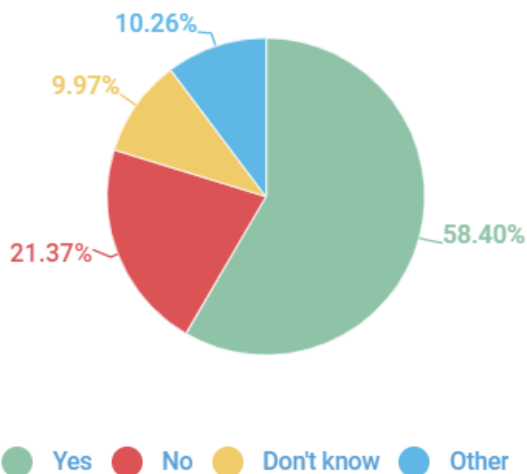
RESULTS

(Employment / Workplace - continued)

“Balancing medical appointments, pain and work is incredibly stressful and difficult. My career is everything and I’m losing it.”

Of those on both short- and long-term disability or in early retirement due to their disease, 58.4% said that it was a consequence of their SpA condition. In the comments section, many indicated that it was a combination of conditions, such as Crohn’s and fibromyalgia, that led to their disability leave or retirement.

Figure 11: Is your Short or Long-term Disability or Early retirement due to SpA?



37% of people who were on short-term or long-term disability said that they had been on it for 0-2 years. 19% had been on disability for 3-5 years, 8% for 6-8 years, 12% for 9-10 years, 13% for 10-15 years, and 11% for over 15 years.



“I can see myself needing to go on disability at some point due to AS and PsA. It’s a struggle to do my job.”

RESULTS

QUALITY OF LIFE

This section was completed by 534 participants.

71% said that their day-to-day life was negatively impacted by their condition. 22% said it was somewhat impacted and 7% said that it was not impacted. Many identified that it was the constant pain and reduced mobility that affected their everyday life. Many people said that chronic fatigue and disturbed sleep also took a toll on their day-to-day life. Some indicated that their daily quality of life was improved with NSAIDs (non-steroidal anti-inflammatory drugs) or biologics.

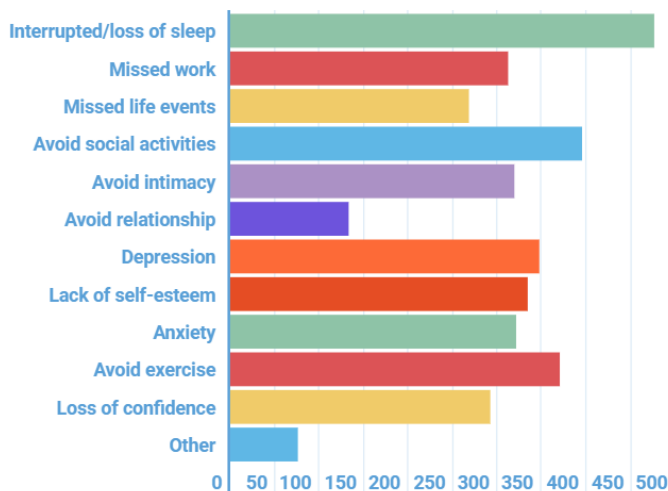
“I’m unable to work, I have to cancel plans all the time. I’m unable to travel. [My condition has] really taken so much from me and my quality of life is poor.”

89.1% of participants said that their condition caused them an interruption in or loss of sleep and 74% said they avoid social events such as picnics, parties, and graduations. Many indicated that they feel isolated, hopeless, and without a purpose.

Upon further investigation, many participants (41%) indicated that they were highly restricted by their SpA condition when it comes to outdoor yard work such as gardening and shoveling snow. Other areas of high restriction were doing physical exercise and cleaning, with a 36% and 31% response rate respectively. Areas of medium restriction included physical exercise, where 36% indicated medium restriction, preparing meals (31%), and engaging in intimate relations (30%). Areas with lowest reported restriction included washing and personal grooming (39%), walking around the house (38%), and lying down (35%). The highest reported activity that posed zero restriction was going to the doctor, where 45% said they were not restricted. Some indicated that all of these activities were highly restricted during flare-ups but only moderately restricted during remission or with treatment. One person indicated that they will choose to refrain from certain activities, such as playing with children, in order to avoid pain from fatigue in the future.

“The disease (for me) is highly variable on how it affects my functional abilities on a day-to-day basis and within a 24 hour time period; [I] may be able to bend over to put my shoes on and later in the day [I] may not be able to remove my shoes independently.”

Figure 12 : Consequences of living with SpA



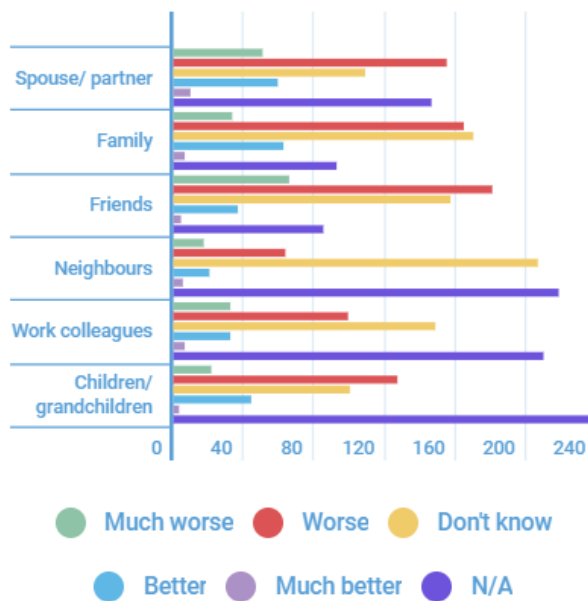
RESULTS

(Quality of Life - Continued)

When asked about how people's relationships were affected by SpA, many indicated that they had worsened. Some indicated that very few people understand invisible illness or really care about it, while others sought out counselling to help them fix their broken relationships. However, another participant said that being able to discuss physical and mental health with family members has improved their relationships and that supportive family and friends build stronger relationships.

When asked about the change in frequency in which people participated in certain activities, the majority reported less frequent participation in exercise, sports, travel, intimate relationships, going to movies and museums, going to cafes, bars and restaurants, and supporting children or grandchildren at school or sporting events. Some even reported that they had stopped participating in these activities altogether. Once again, many indicated that they could increase their participation in the indicated activities with proper treatment and management.

Figure 13 : The Effect of SpA on Relationships



“Living with this condition deeply impacts every relationship because I am irritable. I can’t really plan anything. I feel guilty that I can’t be like a regular mom and wife. It’s very stressful.”

37% said that they do not feel they have a good support network of people to help them emotionally, financially, and physically. Many specified that it was difficult to find a support network who believed and understood them and that they lost many friends and family after being diagnosed. Some said that they feel guilty for being unable to do certain things that those around them can do and for not contributing to income when treatment can be a huge financial burden.



“I can’t do anything anymore. I just want to die. I feel like a burden on everyone and everything.”

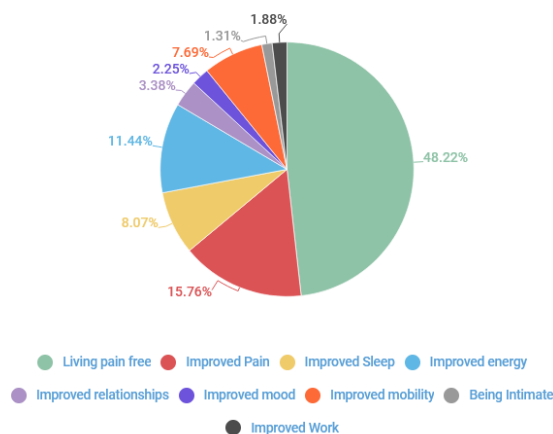
RESULTS

(Quality of Life - Continued)

“The silent withdrawal of those that I used to hang out and do things with is more unbearable than the health condition itself sometimes. It’s as if I’ve outlived my usefulness. It makes me withdraw and not want to trust anyone or anything anymore. Being isolated and alone is rough.”

When participants were asked to rank what was most important to them in regards to quality of life, the majority ranked living with no pain as being most important. Many participants expressed their frustration of being limited by their disease and indicated that it is often the chronic pain that causes these limits. It was clear in the comments that by living with less pain, patients can improve all aspects of their lives and be happier.

Figure 14: Most Important Aspect Regarding Quality of Life



It is clear that SpA conditions burden patients, causing them to constantly need to assess their situation, worry about what tomorrow may bring, and adjust different aspects of their lives in order to live comfortably. Multiple participants indicated that every single aspect of their life has been touched by their disease, both physically and mentally. Many expressed that they can no longer do their favorite hobbies like knitting, cooking, or running, which poses emotional and mental difficulties. It is evident that SpA conditions have contributed to patients losing people they love and have left them feeling lonely and isolated.

Patients indicated that their friends and family have difficulties understanding chronic pain and illness. Some patients feel like a burden as they cause a lot of worrying for their loved ones. This may be attributed to the lack of general knowledge about spondyloarthropathies as one person pointed out by saying that everyone knows about MS and Rheumatoid Arthritis but Psoriatic Arthritis and other types of SpA are relatively unknown. The unpredictability of the disease also impacts quality of life as patients are hesitant to make plans and book vacations because they cannot be certain that they will feel well enough to participate. Even those who are undergoing successful treatment and have improved quality of life have worries about the future. The cost of medications and the financial burden that it may bring to a family unit is a constant worry to patients.

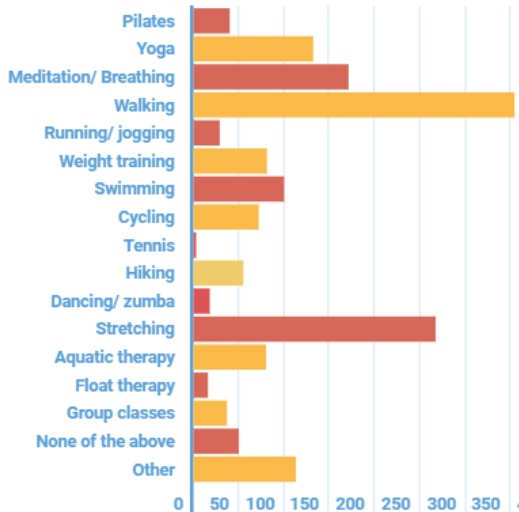
RESULTS

HEALTH & WELLNESS

This section was completed by 513 participants.

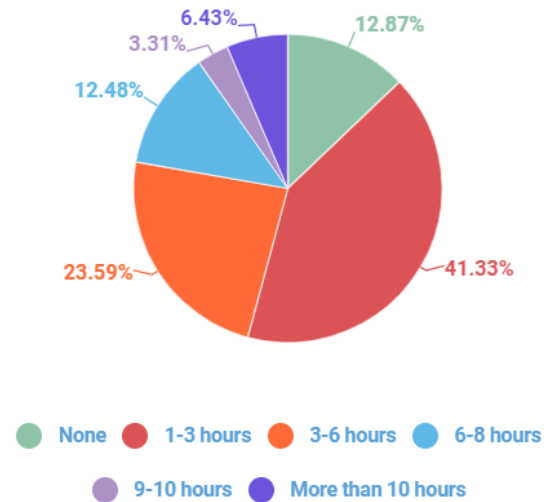
When questioned about physical activities that help manage their condition, the majority of participants indicated that they walk. Many also stretch, meditate, and practice yoga. In the comments section, many said that they practice Tai Chi, while others golf, kayak, and play group sports such as basketball. Some also stated that they used to participate in many of these activities but no longer can due to their disease progression.

Figure 15: Physical Activities Participated in to Help Manage SpA Conditions



Most participants (41%) exercised for 1-3 hours per week, while 13% said they do not exercise at all. When asked why, many participants stated that they have extremely physically demanding jobs so they do not add extra exercise to their daily routine. Many also experience severe pain and/or fatigue that inhibits their ability to exercise. Some said that they had no time or motivation, while others indicated that they do not have the means to afford exercise classes.

Figure 16: Hours of Exercise per Week



RESULTS

(Health & Wellness- Continued)

31% said that they spend under \$100 per year, out-of-pocket, on rehabilitation therapy and exercise to treat and help manage their condition. 23% of participants said they spend over \$1000 per year. When asked to specify, many said that they have gym memberships, attend group classes, see a physiotherapist, and/or a massage therapist. Some specified that their insurance covers part of the cost for a physiotherapist or massage therapist but they still had yearly out-of-pocket expenses for these services. Others said that they would like to access these services but do not have insurance and cannot afford it, especially after paying for their prescription medications. Some participants noted that they decide to spend their money on therapy in order to support their mental health.

It can be observed that a higher percentage of people diagnosed with axSpA, Group A, get 3-6 hours of exercise a week when compared to those with peripheral spondylitis in Group B. Additionally, more people with peripheral symptoms engage in no exercise or physical activity when compared to those with axial symptoms.

Figure 17 : Hours of Exercise per Week (AxSPA Group)

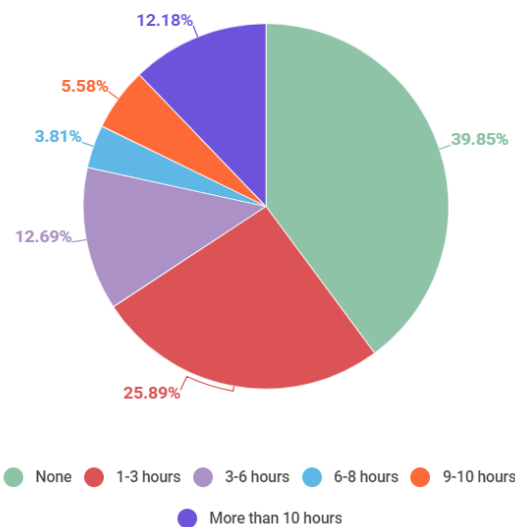
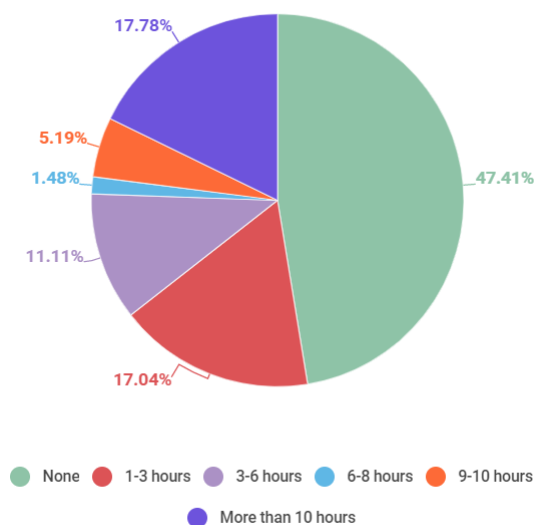


Figure 18 : Hours of Exercise per Week (PSPA & PsA Group)



RESULTS

(Health & Wellness- Continued)

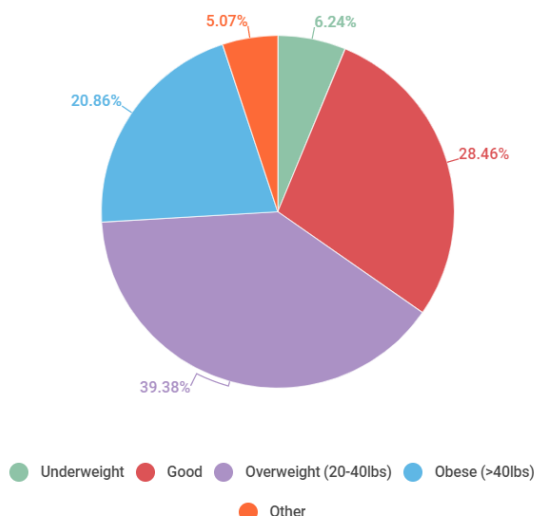
“Everybody should have some type of health and wellness routine. It’s paramount in controlling the disease.”



When asked about their weight, the majority of participants considered themselves to be overweight (39%) or obese (21%). Only 28% of participants considered themselves to have a good weight for their height and body build. In the comments section, several participants indicated that they had gained weight after starting treatment for SpA.

When comparing the answers of individuals for hours of weekly exercise and reported weight category, it is noticed that most people who consider themselves to be overweight, obese, and of good weight all exercised an average of 1-3 hours per week. Of those who participated in more than 10 hours of exercise weekly, most (39%) considered themselves to be a good weight and 33% reported themselves as being overweight by 20-40 pounds. Of those who do not get any form of exercise, 39% said they were obese and 33% said they were overweight.

Figure 19 : Reported Weight Classification Based on Height & Build

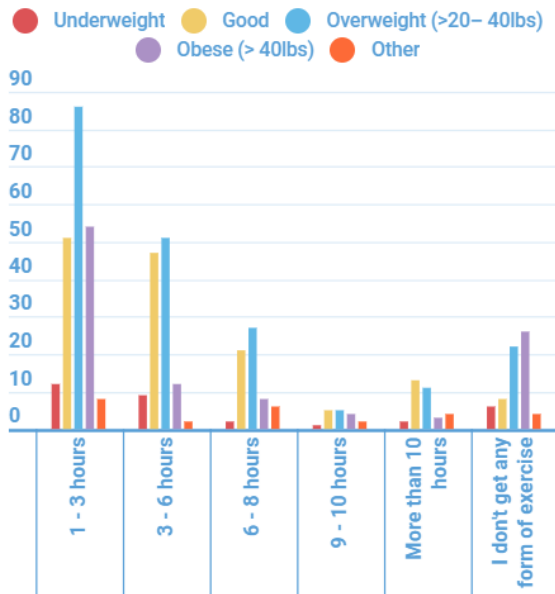


“As much as this is needed for us to feel well, there are obstacles that prevent it. Mostly in terms of finances as we have to prioritize what we spend our limited funds on. I earn less than half of the poverty level. The basics (food, shelter, etc) are all above our own personal well being.”

RESULTS

(Health & Wellness- Continued)

Figure 20: Reported Weight Category vs Hours of Weekly Exercise



70% of participants said they were non-smokers. 3% report smoking socially, 1% smoke fewer than 10 cigarettes/week, 3% smoke 10-20 cigarettes per week, 4% smoke 21-60 cigarettes per week, and 5% smoke over 60 cigarettes per week. 13% said they were ex-smokers and 1% were regularly exposed to secondhand smoke.

46% of respondents reported that they do not consume alcohol. 42% consume fewer than 5 drinks/week, 8% consume 6-10 drinks per week, 3% consume 11-20 beverages per week, and 1% consume more than 20 drinks per week. Additionally, 19% said that they sometimes drink to relieve pain or alter their mood. When asked to elaborate, some said they used to drink alcohol to alter their mood but no longer do so as it worsens their condition. Others said they use alcohol to help them sleep.

When asked to reflect on their overall health and wellness, many said it's hard to manage their condition, comorbidities, medications, and overall health. Some said they felt they would be healthier if physiotherapy was included in their provincial insurance plan. Others stated that by improving their diet and adding more exercise to their routine they felt they had a better quality of life. The financial burden of physiotherapy and group fitness classes was a common theme. Many stated that they would like to be more active and healthier, but lack resources, guidance, motivation, or energy to do so. One young participant expressed their desire for more low impact and appropriate exercise classes for young people as many programs are aimed at the older population.



“Not always easy to motivate myself to move and stretch when feeling weak, tired and in pain but I have seen the importance of getting my body moving. However I am limited with what exercises I can do.”

RESULTS

PHARMACOLOGIC & NON-PHARMACOLOGIC TREATMENT

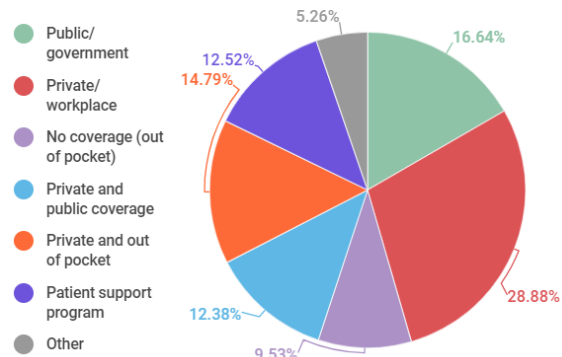
This section was completed by 473 people.

When asked about non-pharmacologic treatments (those not requiring a prescription from a physician) used to manage their condition, 64% said they walk, 48% use diet and nutrition, 41% use massage therapy, and 40% use physiotherapy. Additionally, 32.6% use cannabis and 26% use meditation. Many also indicated that they do mild stretching and take nutritional supplements. When asked how they pay for these non-pharmacologic treatments, 77% said out-of-pocket, 29% said with private insurance, 2% with public coverage, and 8% used a combination of public and private insurance. Of the 6% who answered "other", many said they use a combination of private insurance and pay out-of-pocket.

42.9% said they pay for their prescription medication using private/workplace insurance. In the comments section, some said they used a combination of public and patient support programs sponsored by pharmaceutical companies. Others said their work did not have benefits but their partner's job covered prescription medications. Several participants indicated that they do not take prescription medications as they are too expensive or only take them when needed to offset costs.

"I am unable to do many things recommended by my doctor because of the cost (physiotherapy and massage therapy). I can't afford it even though I know it is helpful. The government should pay for these things for people with AS."

Figure 21: Coverage for Prescription Medications



"No prescription medication. I use Ibuprofen when the pain is bad. My alternative tablets help with pain and mobility but are very expensive."

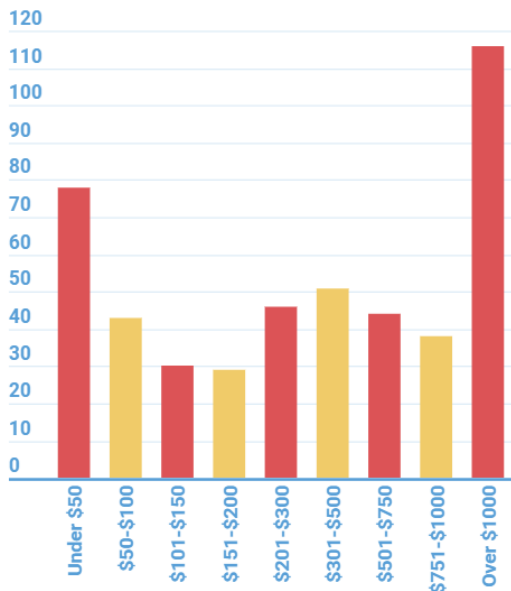
RESULTS

(Pharmacologic & Non-Pharmacologic Treatment - Continued)

Of those who do not have private insurance, 71% said that the lack of private insurance impacts their ability to participate in non-pharmacologic treatments, such as massage therapy and seeing a chiropractor. One university student indicated that the cost of tuition and living is incredibly high, so they do not have extra money to spend on such treatments. Others said that while they do have some form of private insurance, it does not cover enough to use these treatments on a regular basis. Many who have private insurance indicated that cannabis gives them the most relief, yet it is not covered.

The majority of participants (58%) were taking biologics, including biosimilars, to treat their SpA condition. 47% were taking prescription NSAIDs (non-steroidal anti-inflammatory drugs). In the comments, many said that they cannot take some of these medications due to allergies or other comorbidities. Some participants mentioned trying many different medications with little success. Others report using non-medical cannabis to help with their condition.

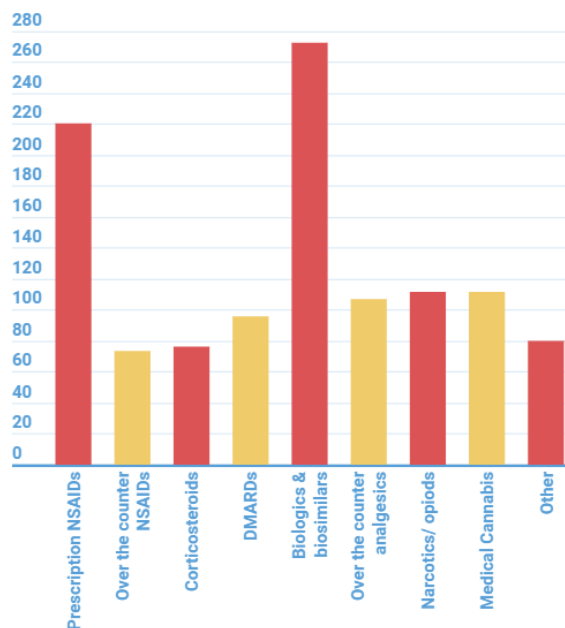
Figure 22: Yearly Out of Pocket Cost for Pharmacologic Treatments



Most respondents (25%) said they spend over \$1000 per year on pharmacologic treatments, including both prescription and over-the-counter. Many specified that these costs were mostly associated with copays and deductibles for their medications, as well as the cost of cannabis.



Figure 23: Prescribed Pharmacological Treatments for SpA Conditions



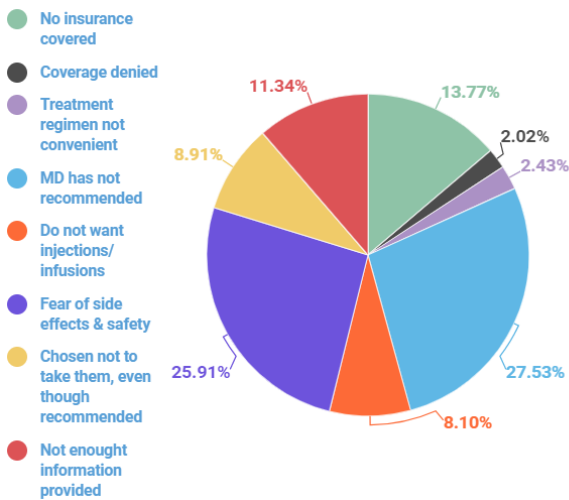
RESULTS

(Pharmacologic & Non-Pharmacologic Treatment - Continued)

Of those prescribed a DMARD (disease-modifying anti-rheumatic drug), the majority had been prescribed methotrexate. Many had also been prescribed sulfasalazine. Humira was the most commonly prescribed biologic, followed by Enbrel, Simponi, and Cosentyx. Of those prescribed either a biologic or a biosimilar, 12% were taking a biosimilar. For the 247 people who had not tried a biologic, the main reasons included not being recommended by a physician and the fear of the side effects and safety.

In contrast, when asked about biosimilars, 38% had no knowledge of biosimilars. 23% had very little knowledge of biosimilars, 29% had some knowledge of biologics, and only 9% were very familiar with biosimilars. When asked under which circumstances patients would feel comfortable switching from a biologic to a biosimilar medication, the majority said they would do so if it was recommended by a physician. Many emphasized their concerns regarding the government forcing switches to biosimilars due to lower costs, while some indicated they were forced to switch and failed on the new medication. Some said that they would require strong scientific evidence before switching, while many indicated they would not switch if their biologic was working well.

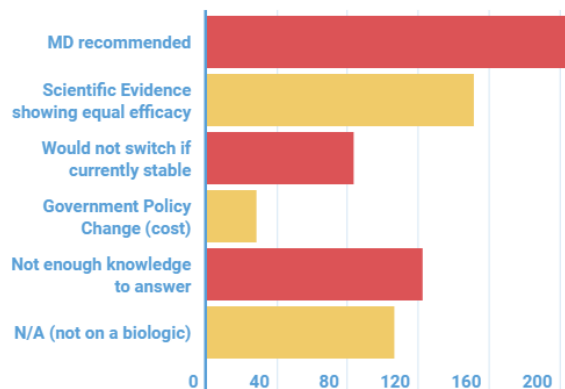
Figure 24: Reasons for not Trying a Biologic



"There should be more information available about biologics. I was afraid to start for years and when I did start on them they worked so well. I wish I had gone on them years ago."

When asked to evaluate their level of knowledge on biologics, only 37% of participants said they were very familiar with them. 41% said they had some knowledge of biologics, 16% said they had very little knowledge of biologics, and 6% had no knowledge of biologics. In the comments, many said that they were knowledgeable and acknowledged that many of their friends living with SpA had great results from their biologic, but were too scared of the side effects to try them. Others said that they did a lot of research in order to become familiar with them.

Figure 25 : Situations in which Patients Would be Comfortable Switching to a Biologic



RESULTS

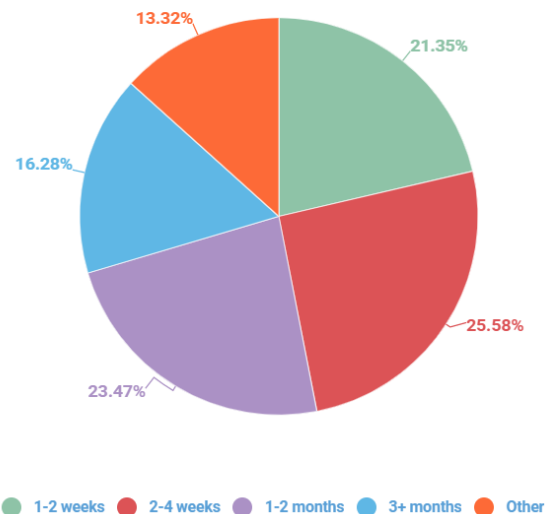
(Pharmacologic & Non-Pharmacologic Treatment - Continued)

When asked about the patient support programs that pharmaceutical manufacturers offer, 52% said it was important for them. In the comments, some stated that it helped them afford the treatment, while others received kits to transport, store, and dispose of their needles which they found valuable.

76% said they felt involved in the decision of which medication their physician would prescribe for them. Some added comments saying that they felt involved but also limited due to their insurance policies. 88% said that they feel comfortable speaking to their rheumatologist or treating physician about dissatisfaction with response to the medication they are taking and the side effects they are experiencing. However, several participants stated that they don't bother discussing it as the answer they often hear is "there is nothing I can do."

When asked about the expected time to see results of a prescribed medication, the majority (26%) said 2 to 4 weeks. In the comments, many said it depends on the medication as NSAIDs can be almost immediate whereas biologics may take several infusions. Some also said that they were still waiting to feel the results of their medication while others wished it would be a shorter time frame.

Figure 26: Expected Time to See the Results of a Prescribed Medication



In the concluding remarks, many participants expressed their frustration with insurance companies when trying to attain a biologic medication. Many insurance providers require patients to fail on first-line treatments before being upgraded to a biologic, which can be very frustrating for a patient. Participants also noted that it was becoming more difficult to receive narcotic analgesics due to the ongoing opioid crisis in many provinces. Many noted the desire for unbiased information regarding the different treatment options so that they can be better prepared to discuss drugs with their treating physician. Multiple participants stated their desire for universal pharmacare that could help them access their costly treatments.



RESULTS

COMPLICATIONS

The questions in this section were answered by 466 participants.

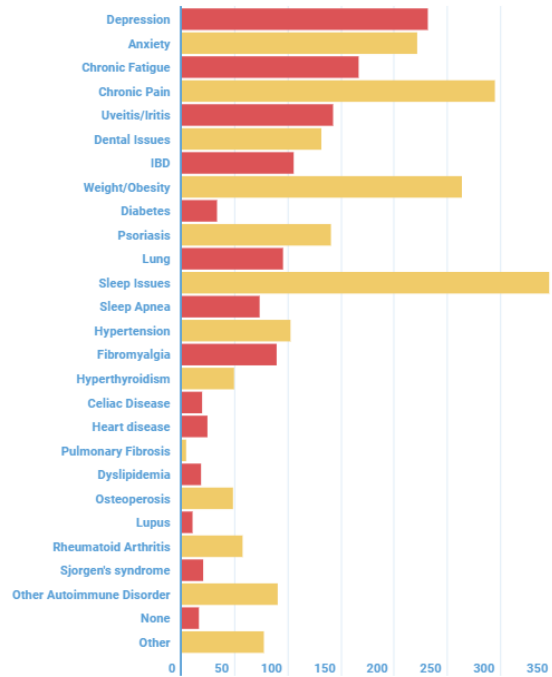
59% of respondents reported that their rheumatologist regularly asks them about additional complications such as depression, fatigue, and gut issues. However, several participants stated that they, as the patient, must always make a point to bring it up to their physician. It was noted that often rheumatologists seem to be more concerned with pain management and continuing function and do not necessarily address other health concerns, particularly mental health.

"My rheumatologist never asks about depression and fatigue. When I bring it up, it gets brushed off".

44% of participants said that they often leave their appointments with questions they intended to ask but forgot to. To avoid this, many indicated that they make a list of questions prior to their appointments in order to not forget.

When asked to identify which complications apply to them, sleep issues (65%), chronic pain (63%), depression (50%), and anxiety (47%) were the most prevalent conditions. In addition to the 23% who said they live with inflammatory bowel disease, many participants indicated that they have other gastrointestinal issues such as irritable bowel syndrome, gastritis, and ulcers. Other prevalent conditions in the comments include weight issues, migraines, vertebral disc herniations, and hypertension.

Figure 27: Complications among SpA Patients

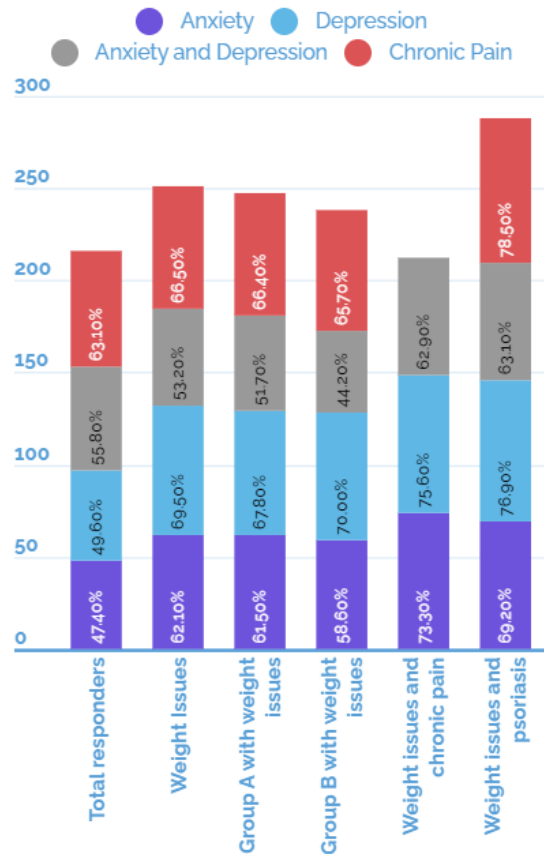


RESULTS

(Complications - Continued)

Of those who responded to this section, 203 (44%) people said they had weight issues. In order to further explore the combined effects of spondyloarthritis and weight issues along with other comorbidities on mental health, we compared various categories using percentages. Those who reported weight issues had a higher percentage of anxiety, depression, and chronic pain when compared to the total responses to this question. The prevalence of combined anxiety and depression was higher in the general population than with those with weight issues and those in Groups A and B with weight issues. However, those who said yes to weight issues and chronic pain or psoriasis had higher percentages of anxiety and depression separately and combined. Additionally, those who reported having psoriasis had the highest percentage of chronic pain.

Figure 28: Comparison of Chronic Pain, Depression, and Anxiety in Different Groups



"The other conditions that come with this condition can be more troublesome and expensive to treat. There gets to be multiple doctors and appointments which wear you out."

Note:

Group A = Responders diagnosed with AS or axSpA or nr-axSpA

Group B = Responders diagnosed with PSpA or PsA

"It's awful, the complications... can be worse than the arthritis. Iritis is absolutely debilitating, life stops until [it is] treated. My newly emerging psoriasis and complications with staph infections is embarrassing, painful, itchy and really mentally consuming."

RESULTS

(Complications - Continued)

Over 300 participants said that they experienced sleep issues. Upon further investigation, it was found that many (26%) said that nothing helps with their sleep. Many others used cannabis (24%), prescribed sleeping pills (20%), and exercise (19%) to cope with their interrupted sleep.

166 participants said that they suffer from chronic fatigue syndrome. When asked how they manage their fatigue, the most common response was exercise. Diet and nutrition were also common answers. However, the majority of participants said they have yet to find something that helps them efficiently manage their fatigue. Many said that taking naps or drinking coffee helps them get through the day. A few participants noted that meditation and mindfulness also help.

"The other conditions that come with [Spondyloarthritis] can be more troublesome and expensive to treat. There gets to be multiple doctors and appointments which wear you out."

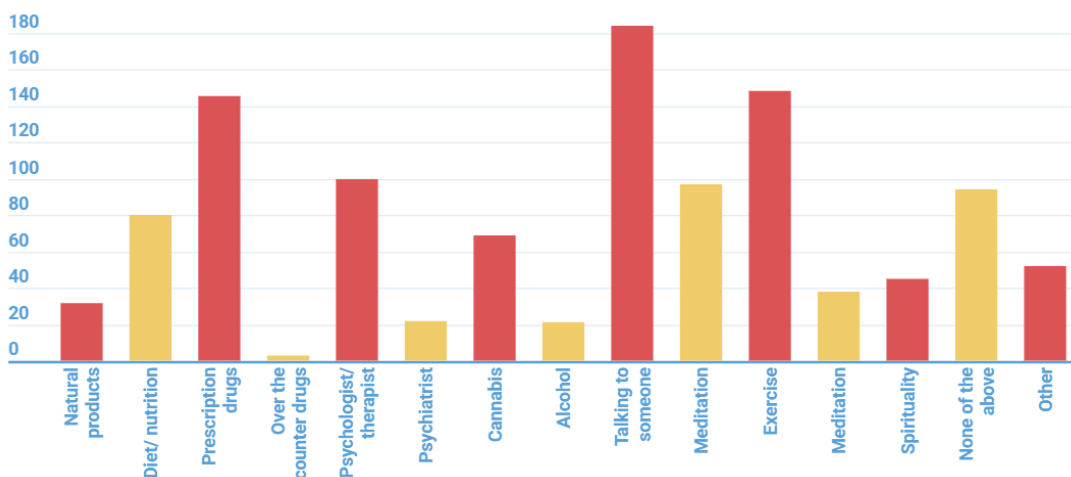
Over 400 people said they suffer from either depression, anxiety, or both. When asked how they cope with this, many (40%) said talking to friends, family, or a spouse. 32% said they use exercise to cope and 31% said they take prescription medications. In the comments, some said they cope using hobbies such as choir, art, and dancing. Some also said they practice mindfulness and journaling.



"My mental health is horrible. I suffer from depression and anxiety. Most days I just want to die. It affects every aspect of my life."

Additionally, it was found that those who suffer from psoriasis have a high prevalence of anxiety, depression, and combined mental health issues. 29.1% of Group A suffered from combined depression and anxiety, compared to 52.5% of those in Group A who also have psoriasis. A similar trend was found in Group B.

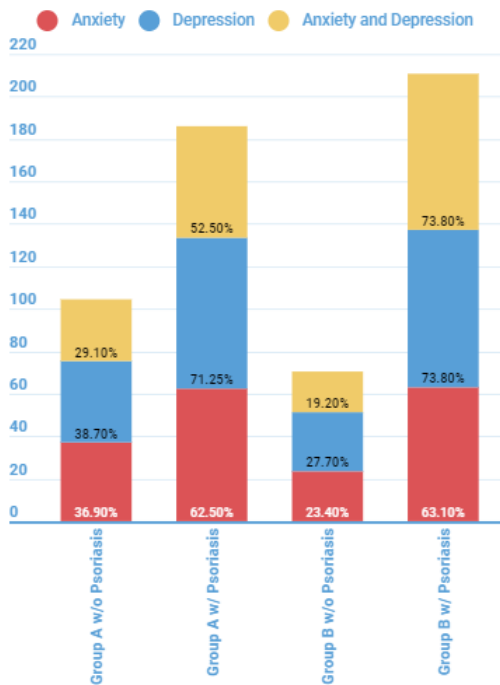
Figure 29: Coping with Anxiety & Depression



RESULTS

(Complications - Continued)

Figure 30: Effect of Psoriasis on Mental Health



For those who experience pain, 45.5% said they use an over-the-counter medication in addition to their prescribed treatment. 41.9% use exercise to cope with their pain and 39.7% use additional prescription medications. Many commented that they use hot or cold therapy to help with their pain, some practice yoga and stretching, while others use CBD oil and cream. One participant noted the importance of sleep, rest, and patience.

Overall, the presence of complications and comorbidities is an additional stressor to SpA patients. Many pointed out that the complications are sometimes more burdensome than the Spondyloarthritic condition. Additionally, these complications lead to increased trips to the physician and more medications which causes frustration to patients.

OBSERVATIONS & RECOMMENDATIONS

IMPACT ON QUALITY OF LIFE

Through an analysis of the results and comments made by participants in this survey, it became increasingly clear that the quality of life of individuals living with SpA is greatly affected by their condition(s). Many participants indicated that every aspect of their life has been touched by their disease, both mentally and physically. The majority of people who participated in this survey reported that their day-to-day lives have been negatively impacted by SpA, with constant pain and chronic fatigue largely responsible for disturbances in their everyday lives. The consequences of SpA that many experience include a loss or disruption in sleep, avoidance of social activities and exercise, feelings of isolation and hopelessness, and worsening relationships.

It is clear that SpA conditions burden patients, causing them to constantly need to assess their situation, worry about what tomorrow may bring, and adjust different aspects of their lives in order to live comfortably. Many expressed that they can no longer do their favourite hobbies like knitting, cooking, running, or working in the garden, which poses emotional and mental difficulties. The unpredictability of the disease also impacts quality of life as patients are hesitant to make plans and book vacations because they cannot be certain that they will feel well enough to participate. Even those who are undergoing successful treatment and have improved quality of life have worries about the future. The cost of medications and the financial burden that living with SpA may bring to a family unit is a constant worry to participants. In addition to financial concerns, individuals also report that SpA has contributed to the loss of people they love, leaving them feeling lonely and isolated. Many participants indicated that their friends and family have difficulties understanding chronic pain and illness, and some individuals report feeling like a burden as they cause a lot of worry for their loved ones.



RECOMMENDATIONS

Although there is currently no cure for SpA, there are options to improve the quality of life of individuals living with spondyloarthritic conditions. The observations and recommendations of the CSA are as follows:

- 1** Access to rheumatologists, faster diagnosis and treatment intervention can help delay disease progression and irreversible damages. We recommend more training on Spondyloarthritis be given to medical students and more education opportunities be available to educate healthcare professionals on the symptoms and management of spondyloarthritis.
- 2** Many participants expressed their frustration of being limited by their disease, and indicated that it is often chronic pain that causes these limitations. Participants suggested that living with less or no pain would greatly improve all aspects of their lives, increasing happiness and participation in various activities (e.g., exercise, sports, travel, intimate relationships, etc.). Some indicated that their daily quality of life was improved with NSAIDs or biologics. We recommend patients have equitable access to services and treatments to help with symptom management.
- 3** Several participants suggested that some of the difficulties they face with SpA may be due to the lack of general knowledge surrounding spondyloarthritic conditions (e.g., lack of understanding from family and friends, physicians unfamiliar with treatments, etc.). Expanding outreach to further educate healthcare professionals, family members/friends, and the general public on the symptoms and complications living with SpA are essential for raising awareness and understanding of spondyloarthritis.
- 4** There continues to be too many individuals living with SpA unaware of the options available to them. Comprehensive information and resources could help people be more familiar with and assess options that could positively improve their outcomes and lead to informed discussions with their healthcare professionals. Our recommendation is to continue developing resources to educate individuals and raise awareness on the diagnosis, treatment, and management of SpA.
- 5** There remains to be too many Canadians who lack access to treatments and services key to helping manage their condition. Public drug programs across the country should make all medications available to patients with reasonable criteria. Private insurers should have accommodations available for people diagnosed with chronic conditions.

RECOMMENDATIONS

(Continued)

We hope that this report will provide the groundwork for education, awareness campaigns, and programs surrounding SpA, in addition to promoting further research in the field of chronic inflammatory diseases. This report also provides a foundation for future assessment of progress towards the goal of optimizing care and improving the quality of life of individuals living with Spondyloarthritic conditions.

“I wish to be euthanized. It's horrible living with this condition.”



“We need better diagnostic criteria so patients, especially female patients are not waiting years or decades for a diagnosis and being treat like they are lying.”



“There is a lack of understanding and awareness of this condition. People have never heard about it and can't even begin to understand how it feels.”



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abbvie



Lilly