SPONDYLOARTHRITIS

AND THE IMPACT OF CAREGIVING

Presented by:

Canadian Spondylitis Association

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Introduction

The **Canadian Spondylitis Association** is a national not-for-profit organization led by dedicated staff and a committed Board of Directors who are diagnosed with a Spondyloarthritic condition or have a loved one living with a condition committed to furthering the CSA's Mission. We are a resource and advocate for the Spondyloarthritic community and their families to improve patient care and quality of life.

The number of Canadians living with Spondyloarthritis* is on the rise. With the increasing number of Canadians being diagnosed and affected by axial and peripheral Spondyloarthritis, it is essential we have credible, valuable and relevant resources and programs available to support the needs of the growing community and the thousands at risk of being diagnosed.

The initiatives we undertake and the events we support are evaluated against our strategic goals to ensure we remain focused on the work that positively impacts the outcomes, journey and quality of life of individuals living with; and at risk of being diagnosed. To endorse our mission, we rely on broad community engagement. We look to increase and diversify our funding, engage volunteers with purpose and pride and expand our partnerships to include the healthcare professional community.

Our goals are clear - we will remain focused on supporting people today while changing the future. We will fulfill our mission through four pillars of activity :

- Education and information – We provide credible and relevant resources and programs to inform and empower Canadians to guide their journey and improve patient outcomes.
- Advocacy – We represent the patient voice on health issues and access to services and medications.
- Awareness – We deliver innovative programs and campaigns to raise awareness of Spondyloarthritis and educate the general population on how debilitating these conditions can be.
- Support – We provide resources to engage Canadians in learning, sharing and supporting one another to reduce the impact Spondyloarthritis has on people.

We recognize there are gaps in resources for patients, their loved ones and healthcare professionals. The CSA is committed to bringing more information, programs and events to the SpA community. We want to reach all Canadians affected by Spondyloarthritis and will advocate on their behalf for better care, improved outcomes and access to treatments and services. We support research in any capacity we are able and will continue to strengthen this capability.

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* Axial Spondyloarthritis, Peripheral Spondyloarthritis, Ankylosing Spondylitis, Enteropathic Arthritis, Psoriatic Arthritis, Reactive Arthritis, Undifferentiated Spondyloarthritis, Juvenile Spondyloarthritis

EXECUTIVE SUMMARY

Spondyloarthritis (SpA) describes a group of inflammatory arthritic diseases with common features, including inflammation of the spine, eyes, skin and gastrointestinal tract. Oxford Rheumatology reports that approximately 1% of the world's population is affected by SpA. Over 300,000 Canadians have been diagnosed with a Spondyloarthritic condition. These conditions are chronic and persistent. They may also come and go, in periods of flare ups and remission. They can be painful and debilitating. Symptoms may present themselves and go undiagnosed for several years. The average age of diagnosis is between 17 and 25 years old for most SpA conditions. Due to the complexity of the disease, it takes an average of 7 to 10 years to be diagnosed.

SpA impacts most aspects of a patient's life, including their ability to work and to maintain both social and intimate relationships. With more severe disease progression, there comes a greater impact on the caregiver and family unit. Due to the variability of the disease, caregivers play different roles ranging from moral support to full time care.

The Canadian Spondylitis Association (CSA) is committed to supporting both Canadians living with SpA and their loved ones. In June of 2019, the CSA launched a survey to gain a stronger understanding of how the lives of caregivers for those diagnosed with SpA are impacted. The survey also aimed to assess where caregivers access resources and support, and questioned respondents in order to better understand what types of topics and information are valuable to a caregiver.

Survey highlights:

- 68% of caregivers do not share duties with anyone else;
- 44% of caregivers use resources to cope with their caregiving role, while 55% of respondents said they would access resources if they were available and accessible;
- 72% of caregivers have experienced stress due to their role;
- 55% of caregivers want to see resources on emotional and mental health;
- Social life, finances and vacation time were the most impacted areas of life for caregivers.

The survey results confirm that the impact of SpA on individuals providing care is significant. The need for a wide range of resources to be available and easily accessible to support caregivers to improve quality of life is validated throughout the report.

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BACKGROUND

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 is also sometimes referred to as spondylitis and spondyloarthropathies. This group is clinically and genetically related but has distinct entities with several genetic, prognostic and therapeutic differences. We don't know what causes spondyloarthritis. SpA often starts in the teen years and early twenties. It is unusual for it to start after age 45. Historically it was thought that ankylosing spondylitis affected more males than females. However, today we are learning that it is affecting the sexes more equally and that women have a high disease burden as well. There is currently no cure.

The main similarities that can occur with any type of spondyloarthritis are:

- Inflammation in the pelvis and spine that usually causes inflammatory back pain
- Pain and/or swelling of any joint in the body (hips, knees, ankles, feet, hands, wrists, elbows, shoulders, etc.)
- Uveitis/iritis, the rapid onset of marked pain and redness in one eye at a time
- Psoriasis
- Inflammation of the intestine (Crohn's disease, ulcerative colitis, undifferentiated colitis)
- Dactylitis, or "sausage digits," inflammation along the tendons of the fingers or toes
- Enthesitis, inflammation where tendons and ligaments meet the bone; this commonly occurs at the back or bottom of the heel

Two Classification of Spondylitis:

1. Traditional SpA group ofdiseases includes:

- Ankylosing spondylitis (AS)
- Psoriatic arthritis (PsA)
- Enteropathic arthritis (arthritis associated with inflammatory bowel disease or IBD)
- Reactive arthritis (ReA)
- Juvenile idiopathic arthritis that is enthesitis related arthritis (JIA-ERA)
- Undifferentiated spondyloarthritis (USpA)

2. Newer SpA Classification:

- Axial spondyloarthritis (AxSpA)
  - Axial spondyloarthritis (AxSpA) affects the spine and sacroiliac joints (the joints between the pelvis and the sacrum or base of the spine).
- Peripheral spondyloarthritis (pSpA)
  - Peripheral spondyloarthritis 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 on bones (enthesis). It includes psoriatic arthritis, reactive arthritis and enteropathic arthritis or inflammatory bowel disease.

Spondyloarthritis’ Two Other Conditions

Two other conditions fall under the classification of spondyloarthritis. The first is enthesitis-related arthritis (ERA), which is a type of juvenile idiopathic arthritis. Juvenile means beginning before age 16. JIA-ERA was known as juvenile spondyloarthritis (JSpA).

The second is undifferentiated spondyloarthritis. Undifferentiated spondyloarthritis describes someone with all the features of spondyloarthritis but without the confirming characteristics.

Although spondyloarthritis is a form of inflammatory arthritis, it differs from rheumatoid arthritis (RA) because people with SpA do not have rheumatoid factor antibodies in their blood. They are seronegative whereas those with RA are seropositive.

Spondyloarthritis in Canada

It is estimated that SpA affects at least the same number of Canadians as rheumatoid arthritis, which is 1 in 100, but it is difficult to determine the exact prevalence due to underdiagnosis. According to the Spondylitis Research Consortium of Canada, SpA was understudied in Canada until recently. The prevalence of ankylosing spondylitis is estimated to be 0.5% of the Canadian population and 0.25% of the population is estimated to be affected by Psoriatic Arthritis. The frequency of axial spondyloarthritis is about 1.4% of the population.

Most Canadians living with SpA are also affected by chronic pain, mental health issues, chronic fatigue and sleep disturbances. Due to the varying presentations of the disease and comorbidities, the role of a caregiver varies greatly between patients, ranging from moral support and simple household tasks to complete loss of autonomy and full-time caregiving.

METHODS

The Canadian Spondylitis Association developed on an on-line survey created in Survey Monkey. Questions were reviewed and piloted-tested by two board members of the CSA and two external caregivers who provided lived experience perspective, and assisted with revisions for clarity, comprehensiveness to ensure the questions would resonate with other caregivers.

The only survey eligebility criteria was to care for someone diagnosed with a Spondyloarthritic condition.

The SpA caregiver community was surveyed from June to August 2019. Respondents were asked 23 questions; a mixture of open- and closed-ended questions. Questions were designed to gain insights on how caring for someone with SpA impacts life – socially, mentally and economically. The average length of time taken to complete the survey was 10 minutes.

After analysing the results of over 75 respondents, identifying themes and setting priorities, we have a good understanding of how to better support caregivers.

Survey Dissemination

The electronic survey link was disseminated by CSA through various social media platforms (Facebook, twitter, websites) to access a national cross-section of Canadians. It was also disseminated through social media channels by Canadian Association of Psoriasis Patients, Canadian Psoriasis Network, The Arthritis Society and Canadian Arthritis Patients Alliance.

RESULTS

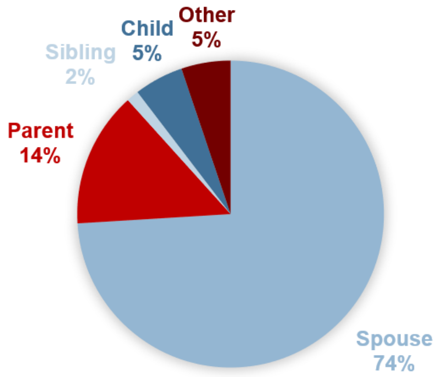
Section 1: Demographics

The first section of the survey was designed to focus on the characteristics of the caregivers in order to better understand them.

The survey was completed by 76 caregivers. Of the participants, 66 were from Canada, 6 from the USA and 4 from Europe. 60% of the participants identify as female and 38% as male.

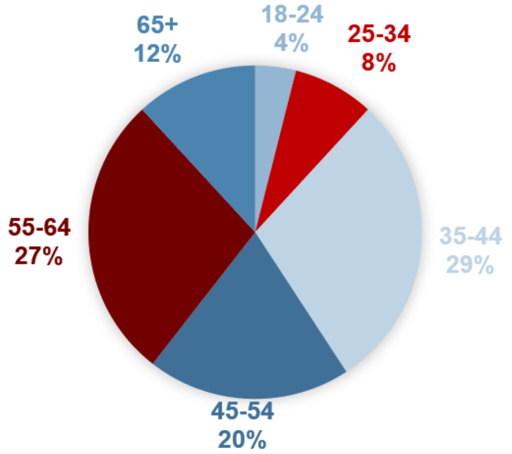
The majority of respondents were the spouse/partner of the person receiving care. Parents, sibling and children of those in need were also caregivers. In the comments section, 3 people indicated that they were their own caregiver and 1 said they were the parent to 2 children living with Ankylosing Spondylitis.

FIGURE 1: HOW ARE YOU RELATED TO THE PERSON FOR WHOM YOU ARE PROVIDING CARE?



29% of the caregivers fell into the 35 to 44-year-old range. 27% were aged 55 to 65 years old, 20% 45-54 years old and 12% were older than 65. A minority were below the age of 34.

FIGURE 2: WHAT AGE DEMOGRAPHIC DO YOU FALL INTO?



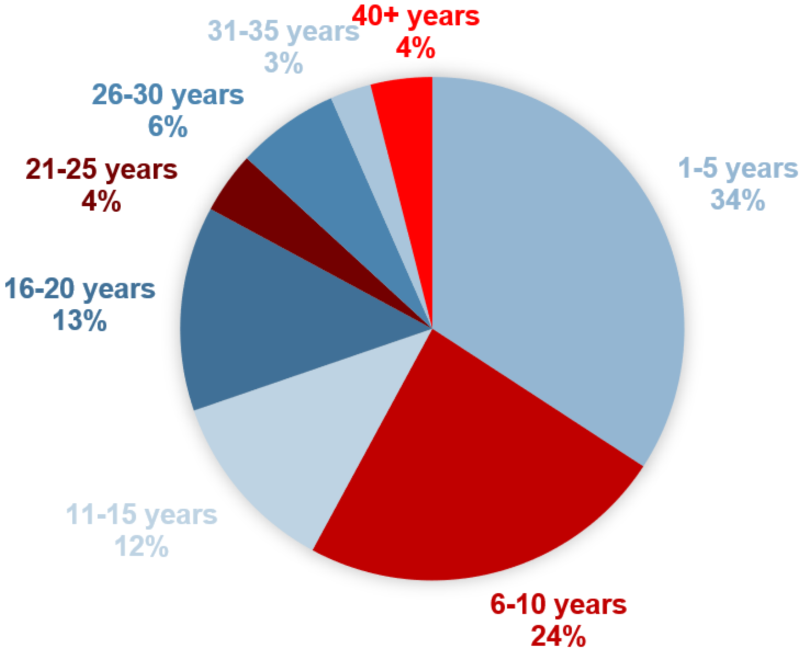
The majority (84%) were providing care for those living with Ankylosing Spondylitis and 15% for those living with Psoriatic Arthritis. Other patient groups represented include Juvenile SpA, Reactive Arthritis and Undifferentiated SpA. It should be noted that 93% of participants indicated that the person they care for has additional conditions and complications associated with their spondyloarthropathy. The most prevalent conditions were chronic pain (65%), sleep issues (51%), chronic fatigue (49%) and depression (45%). Other comorbidities represented include inflammatory bowel disease, hypothyroidism and heart disease.

59% of participants indicated that they themselves have health conditions as well. These include anxiety, rheumatoid arthritis and hypertension.

> ***"I also have Rheumatoid Arthritis so being a caregiver [requires great effort], but we carry on with things because I have to"***
>
> ***-Caregiver***

Most of the caregivers have been providing care for 1 to 5 years. 24% have been caring for 6-10 years and the remainder (40%) for over 11 years.

FIGURE 3: HOW LONG HAVE YOU BEEN PROVIDING CARE?



When asked about sharing their responsibilities, the majority indicated that they do not share the role with someone else.

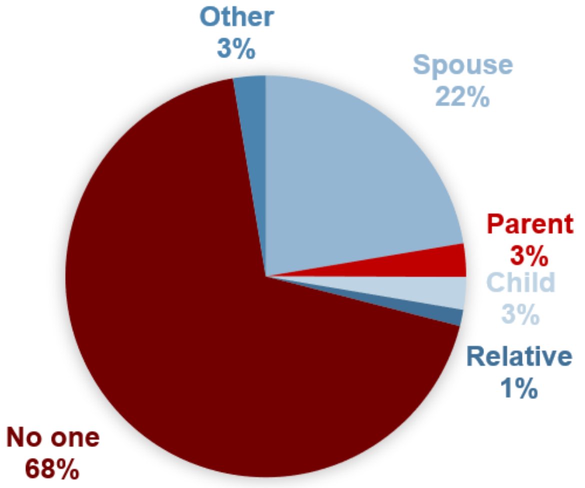


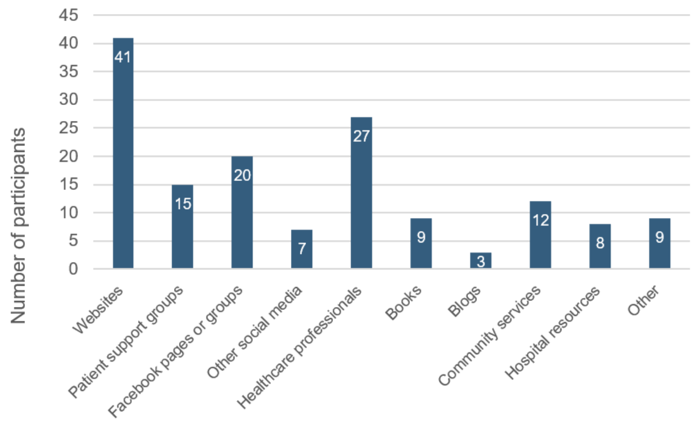
FIGURE 4: WITH WHOM DO YOU SHARE YOUR CAREGIVING

SECTION 2: RESOURCES

The next section focused on resources that caregivers currently use as well as what resources they would like to receive.

46% of participants did not use any resources to help with their caregiving role. 44% of caregivers responded yes to using resources and 10% were unsure. When asked to specify which resources were utilized, participants could select more than one answer.

Figure 5: Where do you access resource(s)?



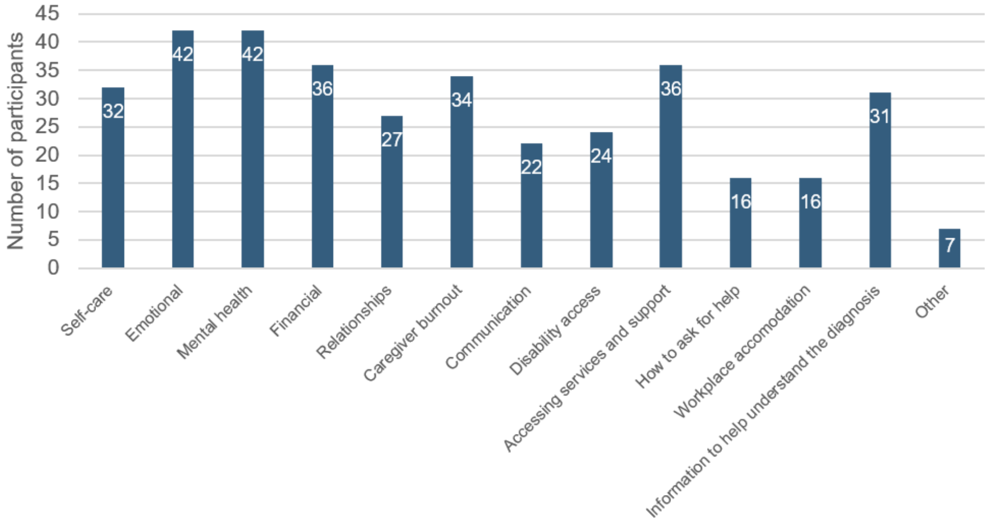
The results showed that websites were the most popular, followed by healthcare professionals. In the comments, one respondent noted that they use extreme caution when accessing information on-line due to the lack of reliable sources.

Of those not accessing resources, many responded that they are unsure of what to access and how to do so. 32% indicated that they are not sure how resources would help them and 20% said that they do not have the time. In the comments, some participants identified that there were no local resources available or that the patient they cared for accessed the resources because they had more time.

When asked to select all topics of interest, mental and emotional health were common themes, each with a 42% response rate. Additionally, 36% are interested in accessing services and support and 34% would like resources regarding caregiver burnout. In the comments, some caregivers stated that they were seeking resources mostly for the person that they are caring for, not for themselves, that any help would be useful, and one said they did not require any resources.

> ***"My entire focus was on him and his quality of life […] It was like I forgot I had a body and mind that mattered because I wasn't in pain or wasn't in the most pain."***
>
> ***-Caretaker***

Figure 6: What topic(s) do you look into or would be of interest to you?

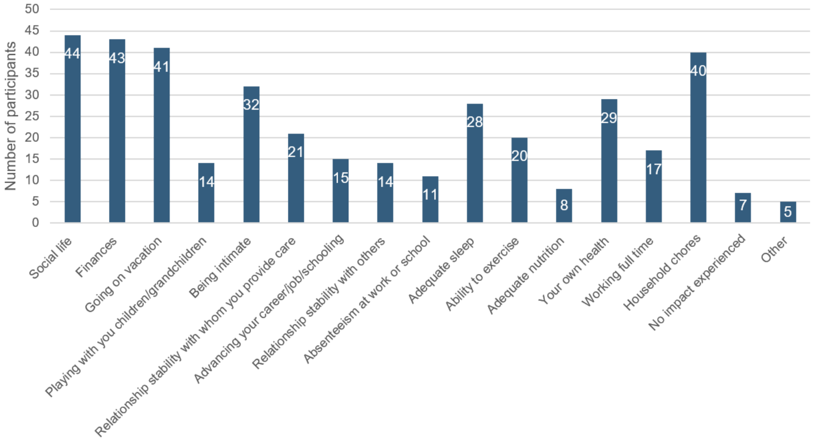


SECTION 3: IMPACT

When asked about caregiving's impact, participants could select all aspects that related to their situation. Only 9% noted that there were no impacts on any aspect of their lives. The areas of highest impact were social life, affecting 58% of participants, finances (57%) and going on vacation (54%). In the comments, participants stated that family planning was affected. Many respondents also indicated that the caregiving does not directly affect their lives, rather it is the constant worrying for their partner or child that takes a toll. In addition, some spouses indicated that they were now the full-time parent to their child as their spouse could no longer care for them.

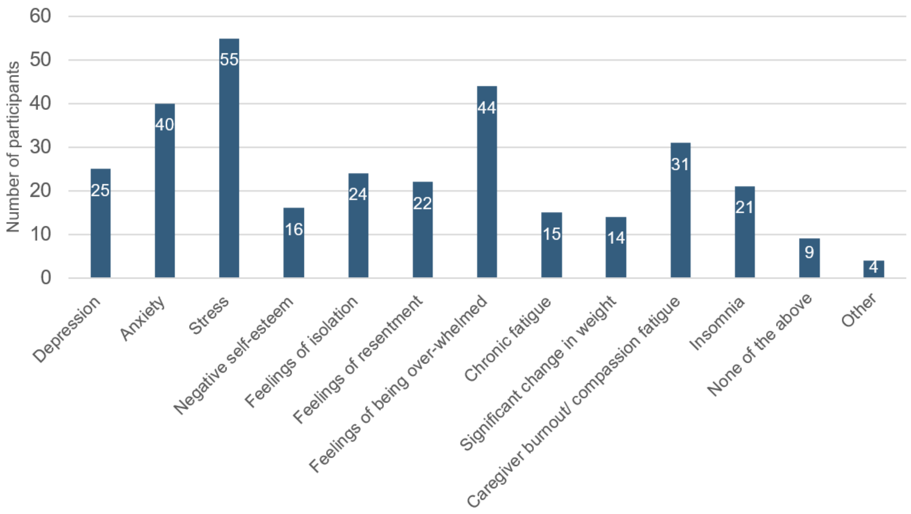
> ***"The impact it has on my spouse is devastating to watch"***
>
> ***-Caregiver***

Figure 7: What aspects of your life are impacted by caregiving?



The majority (88%) responded that their own health has been affected by caregiving. Participants could select all options that applied to them. 72% said they have experienced stress, 58% have felt over-whelmed and 53% have suffered from anxiety.

Figure 8: Have you ever experienced any of the following due to caregiving?



53% of the caregivers said that they have never taken a leave of absence from school or work while 32% had missed work or delayed school due to the responsibilities of caring for a loved one. The remaining 15% indicated that taking a break from work or school was not an option. Some said that their work depends on the number of hours they work, so they cannot afford an absence. Many commented that that they did not have to take long term absences but that they took vacation days to accompany their spouse to appointments for moral support. Many report having to work additional hours or jobs in order to compensate for their partner who is unable to work a full schedule.

When asked about taking time for themselves, 73% responded yes. Common themes were exercising daily, cooking and having a healthy social life with friends. Many also indicated that they find activities to do with their loved one in order to improve both their physical and mental health. Over 20% of respondents said they do not take, or make, any time for themselves - and 7% were unsure, but no justification was given.

> ***"My husband tries to do everything he can without me. He works full time to help cover his medication. Sometimes he needs help putting his socks on, or he is in too much pain to walk the dogs. Our kids and myself help him with this but [it] doesn't affect our lives. We know he will never get better, just worse, right now I consider us lucky that he is able to do what he can."***
>
> ***-Caregiver***

> ***"The focus is always on him because he is in constant pain. I finally realized that in order to avoid burnout and resentment, I had to somehow start building in time for my needs"***
>
> ***-Caregiver***

OBSERVATIONS AND RECCOMENDATIONS

Survey Conclusions

Half the participants indicated that they would access resources if they were provided by the CSA, while 41% were unsure if they would use these. When asked why they were unsure, common responses specified that it would depend if these resources would help meet their unique needs. Some noted that they had limited success with such resources in the past.

> ***“I need more support and education in regard to his condition”***
>
> ***-Caregiver***

When asked to share tips and strategies regarding their caregiving roles, participants identified important themes. These included unconditional love and always supporting the person, regardless of their needs that day. Education and advocacy are also key. Caregivers acknowledged that accepting help is essential as well as taking time for your own personal needs. Some caregivers would like to access counselling that is specialized in relationships during chronic illness. Some identified the desire to find local people to connect with who are going through the same journey. Finally, social media groups and platforms to connect with other caregivers helps to provide support for those who need it.

Observations

It is apparent that Spondyloarthritis has a significant impact on caregivers. Not surprisingly caregivers suffer from stress, anxiety, feelings of being overwhelmed; and suffer from caregiver burnout. Many carry the bulk of managing household chores, childrearing and are responsible for financially supporting their family as their loved one’s illness progresses.

Caregivers would like to have access to information and resources but don’t know where to look or don’t have the time. Developing a central site to refer to information on many different topics of interest would be valuable.

Recommendations

- Develop programs and resources in one central location on topics of interest.
- Promote developed resources through social media to extend reach.
- Educate patients with a diagnosis carefully about the impact their condition has and encourage them to share developed resources with their loved one.
- Create a Facebook page or blog for caregivers – a safe place for them to share, learn and feel supported.
- Bring awareness of caregiver burnout – it is real – don't dismiss it.

We hope that this report will provide the groundwork for education, awareness campaigns and programs in addition to further research in this area. It also provides a foundation for future assessment of progress of caregiver support and recognition.

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Creating a community for caregivers and loved ones

Website:

www.spondylitis.ca

Social:

@SpondylitisCa

Acknowledgements

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Recognized for the survey promotion is the Canadian Association of Psoriasis Patients, Canadian Psoriasis Network, The Arthritis Society and Canadian Arthritis Patients Alliance.