

# Overburdened:

## A Report on the Burden of Psoriatic Disease in Canada

### A Working it Out Scoping Review

Canadian  
Psoriasis  
Network



Réseau  
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# Principal Summary/Abstract

## Introduction

Psoriasis (PsO) is a chronic, immune-mediated inflammatory skin disease presenting as well-defined silver, scaly plaque. Approximately one million Canadians live with the condition, and of these Canadians, plaque psoriasis is the most common form. When referring to all sub-forms and manifestations of PsO collectively, this is known as "psoriatic disease" (PsD). Though every person experiences PsD differently, the findings in this report provide insights into some of the common challenges people in Canada contend with when they live with PsD and the impacts of this disease on the broader society.

## Methods

As part of Phase 3 of Working It Out, a three-year campaign focused on supporting people with PsD in the workplace, this final report summarizes the dominant themes that emerged in the scoping review related to four domains – the burden of PsD on individuals, families, healthcare systems, and society.

## Results

Burdens of PsO range from minor to significant, with individuals expressing concerns about how their condition impacts their families. Lack of understanding of one's PsO or disappointment with treatment options and progress can lead to isolation. Differences emerged between patient and practitioner perspectives when evaluating QoL and ways to improve it. Details of findings on the burden of PsD are detailed in the report according to several clinical, patient-reported tools, including Dermatology Life Quality Index (DLQI); SF-36; Health Assessment Questionnaire (HAQ); Female Sexual Function Index (FSFI).

There is a high prevalence of comorbidity in individuals living with PsD. Regarding, "special areas", while the literature was limited, this review found that nail involvement is not only correlated with poorer outcomes, but also might be of particular concern to Canadians with PsD. Important differences between various groups such as gender and educational status were also observed as being important. Mental health was noted as highly significant in PsD with several studies indicating higher rates of mental illness. The impact on work productivity and activity impairment were greatest in those with higher severity of disease. The impact of work absenteeism and productivity was affected also by access to treatments such as biologics. The literature found that PsO severity is correlated with unemployment, income, and income loss. Psoriatic disease also imposes a significant burden on families, though there was a notable dearth of literature on this topic, indicating the need for further research. Annual treatment costs for PsD vary significantly and PsD comorbidities were associated significantly increased healthcare costs and resource utilization. The cumulative estimated loss of income due to PsO was reported as \$749 million CAD annually which would be more than \$1.1 billion CAD [today](#), indicating that lost work productivity due to PsO not only impacts individuals with PsO, but it has serious implications for the broader economy and society.

## Conclusion

It is apparent from this preliminary report that PsD poses significant burdens to patients broader society. In the next iteration of this report, it will be important to explore how PsD impacts families and healthcare system to better understand the overall impacts of PsD on society at large.

# Background

Psoriasis (PsO) is a chronic, immune-mediated inflammatory skin disease presenting as well-defined silver, scaly plaques that can range from pink colour<sup>1</sup> to purplish or gray, depending on skin tone<sup>1</sup>. Plaques most commonly occur on the trunk, the extensor surface of joints such as the knees and elbows, and on the scalp,<sup>1</sup> though they can occur anywhere on the body. PsO affects 1–3% of the general population, with women being diagnosed a decade earlier than men, on average.<sup>1</sup> Approximately one million Canadians live with the condition, with plaque psoriasis being the most common form.<sup>1</sup> Although there is currently no cure for the disease, there are many effective treatment options to control the disease.<sup>1</sup> Apart from affecting the skin, PsO patients often live with associated inflammatory diseases such as psoriatic arthritis (PsA), inflammatory bowel disease and inflammatory eye disease as well as other comorbidities such as hypertension, type 2 diabetes, metabolic syndrome, and depression.<sup>1</sup>

There are many forms of PsO including plaque psoriasis, inverse psoriasis, guttate psoriasis, erythrodermic psoriasis, palmoplantar psoriasis, and generalized or localized pustular psoriasis.<sup>1</sup> Approximately one third of patients with PsO have psoriatic arthritis (PsA), a chronic, inflammatory arthritis that manifests in the joints, entheses, tendons, spine, skin, and nails. PsA can cause joint pain, joint stiffness, and irreversible joint damage,<sup>1</sup> without appropriate intervention. When referring to all sub-forms and manifestations of PsO collectively, this is known as “psoriatic disease” (PsD).

Individuals with PsD can experience many challenges that have large impacts on their quality of life. Struggles with body image and self-esteem can arise from stigma, shame, and embarrassment socially imposed on people with a visible condition. This can cause emotional difficulties, social difficulties, and mental health conditions such as anxiety and depression. Furthermore,

symptoms such as itchiness, pain, discomfort, and joint stiffness can result in losses of productivity, absenteeism, or extended leave/disability in the workplace. Combined with the steep cost of medications and increased healthcare use, workplace impairment can have a massive impact on the financial well-being of individuals affected by PsD. PsD can also impact the families and loved ones of those affected by the disease, cause increased burden on the healthcare system, and have societal impacts in the context of productivity loss, healthcare consumption, and community resource use.

# Burden of Psoriatic Disease (PsD) – Final Report

As part of Phase 3 of Working It Out, a three– year campaign focused on supporting people with PsD in the workplace, this **final** report summarizes the dominant themes that emerged in the **scoping review** related to four domains – the burden of PsD on individuals, families, healthcare systems, and society:

## 1. Burdens on Individuals with PsD

- Patient–Reported Quality of Life, Health, and Functionality
- Differential Experiences of Health–Related Quality of Life
- Comorbidities
- Special Areas
- At Risk Populations
- Mental Health
- Work Productivity, Absenteeism, Presenteeism
- Financial Implications

## 2. Burdens on Families

## 3. Burdens of Healthcare Systems

## 4. Burdens on Society

- Economic Impact

## 5. Other resources

Findings from grey literature are also summarized to provide additional insights and context to the literature.

Though every person experiences PsD differently, the findings in this report provide insights into some of the common challenges people in Canada contend with when they live with PsD and the impacts of this disease on broader society.

# Methodology

## Study Design

As part of the [Working It Out](#) campaign, the Canadian Psoriasis Network (CPN), the Canadian Association of Psoriasis Patients (CAPP), recently consolidated into Psoriasis Canada (PsoCan), and Unmasking Psoriasis (UP), an awareness group in Saskatchewan, are completing a scoping review (a type of literature review with rigorous methods) to help identify literature on the burden of PsD, specifically to Canadians. A protocol for this forthcoming scoping review has been registered in the [Open Science Framework](#).

## Search Strategy

The literature search was performed by a librarian scientist with over twenty years of experience. The search was broad as to capture burden in various domains of life: to patients, to families, to healthcare systems, and to society at large – including economic burdens. The search was applied to the following databases: MEDLINE, Cochrane (Cochrane Central Register of Controlled Trials, Cochrane Database of Systematic Reviews), Embase, JBI, PsycINFO. The literature searches were peer-reviewed by another librarian using the Peer Review of Electronic Search Strategies (PRESS) Checklist.<sup>2</sup> A sample search from MEDLINE is attached (Appendix 1).

## Inclusion/Exclusion Criteria for the Scoping Review

Literature would be included if:

1. It is concerned with PsD (any type, sub-form, or associated conditions such as PsA);
2. It speaks to burdens of PsD in one (or more) of the following domains: patients with PsD; family members of people with PsD; healthcare systems; society at large;
3. Study is either conducted in, or has findings that are attributable to, Canada;

4. No restrictions on study type;
5. No restrictions on publication date.

Literature would be excluded if:

1. Published in a language other than English or French.

## Literature Screening

The literature was screened by a team established by CPN, CAPP, and UP. Every abstract which the literature search captured was reviewed by two reviewers independently. Each reviewer referred to the inclusion/exclusion criteria, and voted on whether to review the full-text of the abstract or not. This process is then repeated at the full-text stage where reviewers voted whether to include the article in the review. Critical information from these included articles was extracted by the two independent reviewers. If there was initial disagreements between reviewers regarding inclusion of an article, they met to resolve the matter through discussion.\* This screening process was completed through the program, Covidence.<sup>3</sup>

## Content Included in this Report

This report provides a summary of literature captured in our scoping review. The CPN, CAPP and UP plan to also prepare a formal scientific manuscript of the scoping review, reported using the Preferred Reporting Items for Systematic Reviews extension for scoping reviews (PRISMA– which will be submitted for publication in a scientific journal separately.

\* Guidelines on the conduct of scoping reviews which state that discussion OR a third vote can resolve conflicts. A third voter is not required and discussion is recognized as an equally legitimate conflict resolution method: [https://journals.lww.com/jbisrir/Fulltext/2022/04000/Methodological\\_quality\\_guidance\\_and\\_tools\\_in.8.aspx?casa\\_token=7IHQN3m--DYAAAAA:VjJ5V9nB1uhE\\_KHy8Q3jC4X6M1ClqRfHyfnAkqYGQY64Yqtu6SgzCa1UP-PT-lpSeEK018MXHK4zXBVBVhfa3](https://journals.lww.com/jbisrir/Fulltext/2022/04000/Methodological_quality_guidance_and_tools_in.8.aspx?casa_token=7IHQN3m--DYAAAAA:VjJ5V9nB1uhE_KHy8Q3jC4X6M1ClqRfHyfnAkqYGQY64Yqtu6SgzCa1UP-PT-lpSeEK018MXHK4zXBVBVhfa3)

# DOMAIN #1: BURDENS ON INDIVIDUALS WITH PsD

## Patient-Reported Quality of Life, Health, and Functionality

### Impact on Daily Life and Quality of Life (QoL)

Burdens of PsO range from minor to significant, with individuals expressing concerns about mobility, managing pain flares, and being concerned about how their condition impacts their families. Lack of understanding of one's PsO or disappointment with treatment options and progress can lead to isolation, worsened social stigma, a sense of hopelessness, and/or greater impact on daily activities.<sup>5</sup> Moreover, some individuals discussed how PsO disrupted their daily life, and indicated it was challenging to “stay positive” while living with an “invisible disability.”<sup>6</sup> In one study, when people with PsO were asked to rank whether the disease posed a “problem” for their lives on a scale of 1–10, with 1 being “no problem at all” and 10 being a “very large problem,” the mean score was 6.2 and one third describe PsO as posing a “substantial problem.”<sup>7</sup>

In the context of PsA, over 95% (n=1,247)\* of individuals with PsA surveyed reported having experienced musculoskeletal related symptoms within the last year.<sup>8</sup> More than 75% of individuals with PsA said the disease impacted their daily activities, with 62% expressing concerns surrounding their work productivity, and more than half indicating the disease influenced their career path.<sup>8</sup> This is similar to findings in the [Working It Out](#) survey on patient experiences in the workplace which found that more than half of survey respondents said that PsD impacted them negatively at work and that they had concerns about how PsD could impact their ability to stay employed.

PsA can present numerous impairments and limitations, though patients reported that access to certain environmental factors (e.g., medications, healthcare professionals, immediate family and their attitudes, friends, and their attitudes) are helpful in maintaining participation in activities.<sup>9</sup>

Despite these helpful factors, nearly 70% of individuals with PsA (n=887) reported a moderate to major impact on their mental health and more than half said the condition impacted their romantic relationships.<sup>8</sup> Nearly 45% (n=556) reported that the disease had negative impacts on their relationships with family and friends, with one third of individuals indicating they had experienced social shaming over their condition.<sup>8</sup>

Differences emerged between patient and practitioner perspectives when evaluating QoL and ways to improve it. One study found that itch, symptom control, and skin clearance were reported as the top clinical goal for patients whereas practitioners rated “improving QOL” as the most important goal.<sup>10</sup>

An important approach to understanding the burden of chronic conditions, such as PsD is through validated questionnaires that ask patients questions about their lived experience and how living with PsD impacts their daily life. The following summaries provide insight into what several questionnaires used by PsD clinicians revealed about the burden of PsD.

### *Dermatology Life Quality Index (DLQI)*

Data collected using the DLQI suggest that the burden of PsD increases with the severity and extent of skin surface area affected; this results in a greater negative impact on patients' well-being.<sup>11</sup> There was not a clear consensus about whether PsA was associated with higher DLQI compared to PsO alone. One study reported that PsA patients had worse health-related quality of life compared to PsO patients, which a significant difference in DLQI scores<sup>12</sup>; however, another study demonstrated that the mean DLQI score in PsO patients was higher than the mean of those with PsA<sup>13</sup>.

\*Please note that the exact numbers for subanalyses were not always shared and so these were calculated using the percentages shared in the papers' results of the total number of participants. Depending on how authors rounded, these numbers might differ by 1 or 2.

## SF-36

The SF-36 is another questionnaire that measures health-related quality of life (QoL) through eight scales: physical functioning, limitations due to physical health, bodily pain, general health, vitality, social functioning, limitations due to emotional challenges, and mental health.<sup>14</sup> These eight domains all contribute to a physical component summary score and a mental component summary score, with a higher score indicating better QoL.<sup>14</sup> The literature highlighted that the presence of PsA typically negatively impacts physical health more intensely than PsO alone.

Husted et al. found that in patients with PsA, comorbidities such as fibromyalgia, neurological disorders, and obesity were linked to decreases in physical component summary scores, and fibromyalgia and depression/anxiety were linked to decreases in mental component summary scores.<sup>14</sup> These associations held true even after adjusting for disease-related and sociodemographic factors. Rosen et al. compared SF-36 scores in patients with PsO only and in patients with PsA. They found that the physical component summary score was higher in patients with just PsO, signifying higher QoL and less limitations in this domain compared to those who also had PsA. However, there was no difference in the mental summary score between the two groups.<sup>13</sup>

Several studies using the SF-36 were conducted outside of Canada. A study done in Croatia and Denmark found that PsO populations in the two countries had lower mean overall SF-36 scores in all domains except for physical functioning and thus, a lower QoL compared to the reference general population.<sup>15</sup> Similarly, SF-36 mental component summary and physical component scores were below the normative values seen in the general population in both the United States and five European countries (France, Germany, Italy, Spain, UK and collectively called the EU5), although broadly similar between each other.<sup>16</sup>

A shortened version of the SF-36 is called the SF-12, which also examines quality of life through a physical component summary score and a mental component summary score. Compared to the general population, patients with PsO have substantially lower scores on the SF-12; this indicates the negative impact of the disease on physical and mental well-being.<sup>17</sup> Similarly, the SF-12 physical and mental health composite score was lower in PsA patients compared to patients without.<sup>12</sup>

## Health Assessment Questionnaire (HAQ)

The Health Assessment Questionnaire (HAQ) serves as a crucial measurement tool to comprehend self-reported health-related quality of life outcomes. The studies using this metric highlighted that PsA in particular poses negative impacts on health-related QoL.

In a study conducted by Rosen and colleagues, it was found that patients with PsA had HAQ scores that captured poorer health-related QoL compared to individuals with PsO alone.<sup>13</sup> This is connected with the higher level of disability that is experienced due to the impact on the joints. Building upon these findings, Eder et al. (2013) further emphasized that women with PsA suffered from more severe functional limitations and reported a lower QoL compared to their male counterparts.<sup>6</sup> Specifically, women with PsA scored higher on the HAQ, suggesting greater limitations in their daily physical functioning when compared to men.<sup>18</sup>

## Female Sexual Function Index (FSFI)

The Female Sexual Function Index (FSFI) is a questionnaire used to understand sexual functioning in pre- and post-menopausal women.<sup>19</sup> There is evidence that sexual functioning is negatively affected predominantly in women with PsA. In a comparative analysis, individuals with PsA have worse FSFI compared to healthy controls with score averages being 17.44/32 vs 25.49/32, respectively.<sup>19</sup> Among a sample of 21 women who reported having sex in the most recent month, 52.2% of individuals with PsA had sexual dysfunction.<sup>19</sup>

## Other indicators

Other quality of life indicators found in our search included the EuroQol 5 domains (EQ-5D), PSO-LIFE, and PROMIS. The EQ-5D is a QoL instrument that defines health in terms of mobility, self-care, usual activities, pain/discomfort, and anxiety/depression, with 0 representing the worst health state possible and 1 representing the best health state possible (Rosen). Rosen et al. found that PsA patients were found to have a lower EQ-5D and thus, decreased QoL compared to PsO patients.<sup>13</sup>

The *PSO-LIFE* questionnaire is a psoriasis-specific health related QoL tool that asks 20 questions covering aspects ranging from symptoms, to impact on emotional well-being, relationships, and activities and leisure.<sup>20</sup> According to a study by Dauden et al., 47% of active-psoriasis and 7.5% of inactive-psoriasis patients reported their overall health status as being "rather", "quite" or "very" poor, with poorer *PSO-LIFE* score and thus QoL in active-psoriasis patients compared to inactive-psoriasis patients.<sup>20</sup>

*The Patient-Reported Outcomes Measurement Information System (PROMIS)* is a program that measures patient-reported outcomes by covering physical, mental, and social health in comparison to the average population. In a study by Orbai et al., patients with PsA completed questions about 10 categories such as pain interference, physical function, sleep related impairment, and ability to participate socially.<sup>21</sup> They found that in the overall PsA population, the *PROMIS* pain interference, fatigue, function, and sleep were worse than population norms.<sup>21</sup> Additionally, patients with PsA flares had worse scores across all domains compared to no flare.<sup>21</sup>

## Differential Experiences of Health-Related Quality of Life

The literature revealed that PsD's impact on health-related Quality of Life (QoL), as measured through the *Dermatology Life Quality Index (DLQI)*, was worse for Black, Asian, and Hispanic/Latino individuals than for White individuals.<sup>22</sup> This finding was evident regardless of severity of PsD, the treatment the patient was on, or other sociodemographic considerations.<sup>22</sup>

This raises questions about the impact that systemic racism, and other oppressive systems, may play on worsening PsD burden since racialization appears to have an impact on the burden of PsO on QoL even when disease stage/severity are the same. Given that no studies emerged in this review that looked at the impacts of PsO on QoL for Indigenous individuals, this also suggests that there is a lack of research and knowledge about PsD in Indigenous communities.

## Comorbidities

There is a high prevalence of comorbidity in individuals living with PsD. Among these common comorbid conditions are hypertension followed by obesity, diabetes, kidney disorders, and chronic obstructive pulmonary disease (COPD).<sup>23</sup> Statically significant higher rates of hypertension (52.2% vs. 27.3%;  $P=0.027$ ) and anxiety/depression (17.4% vs. 3.0%;  $p=0.048$ ) were noted.<sup>23</sup> The literature showed that comorbidities can also negatively impact work productivity amongst people with PsD,<sup>24</sup> though these comorbid conditions do not necessarily result in additional PsD-related burden and can be independent sources of burden for the patient.<sup>13</sup>



## Special Areas

“Special areas” refer to areas of the body affected by PsD that are understood to be particularly burdensome.<sup>25</sup> These “special areas” generally include: scalp, face, hands, intertriginous areas, genitals and nails. While this report did not capture comprehensive studies on special areas, we acknowledge that these areas have been identified as areas of high burden for people with PsD.

This scoping review found that nail involvement is not only correlated with poorer outcomes, but also might be of particular concern to Canadians with PsD. In a comparative analysis between Americans and Canadians living with PsO, Richette and colleagues found that while musculoskeletal or skin manifestations were comparable, nail involvement was more commonly reported by Canadians.<sup>26</sup> Nail involvement, which can place a heavy burden on individuals with PsD, can also be an indicator of more severe disease. An expert panel asserted that nail involvement has social implications, worsened pain, and negative impacts on activities of daily life (e.g., buttoning clothes or opening bottles) along with social concerns.<sup>27</sup>

Psoriasis on the neck and upper chest area is associated with a higher *DLQI* score, which indicates lower quality of life.<sup>28</sup> Additionally, individuals who found that their stress exacerbated their PsO tended to have psoriasis in areas such as their face, neck, scalp, hands, and genitals, which leads to difficulties with socialization and sexual functioning.<sup>29</sup> Thus, there are additional QoL and psychological burdens of PsO for patients with special area involvement.<sup>10</sup>

Although not a special area mentioned above, PsA patients with enthesitis, or inflammation of sites where tendons or ligaments insert onto the bone, like the heel or toe, can also be disproportionately burdened by their disease.<sup>30</sup> A study by Mease and colleagues found that regardless of the affected location, patients with enthesitis had worse disease activity, worse QoL, higher pain and fatigue scores, and greater work and activity impairment compared to patients without enthesitis.<sup>30</sup>

## At Risk Populations

Psoriasis has a disproportionate impact on certain populations. Educational status affects burden of PsD, where patients with poor or very poor control of PsO were significantly more likely to have finished their education at the high-school level, compared to those with well or moderately controlled disease.<sup>31</sup> Additionally, level of income is associated with PsD, as lower mean household income was found to be associated with moderate or severe PsO compared to very mild/mild PsO.<sup>32,33</sup> Additionally, the use of biologic therapy was significantly correlated with higher income and the availability of full medical coverage.<sup>33</sup>

PsD affects men and women disproportionately, although in different aspects. Men were found to have better QoL,<sup>34</sup> and responded better to treatment with advanced therapy such as biologics and targeted synthetic disease-modifying antirheumatic drugs (DMARDs).<sup>34</sup> However, they were found to develop more severe structural changes in both axial and peripheral joints,<sup>34</sup> had more discriminatory attitudes towards psoriasis, and were overall less informed about psoriasis compared to women.<sup>35</sup> There were contradictions in the literature about the effect of PsD on workplace functioning. One study endorsed that men had less work disability compared to women.<sup>34</sup> However, a second study reported higher work disability in men<sup>36</sup> and a third study reported that psoriasis had a greater impact on occupational functioning among men compared to women as they were more afraid of losing their job and felt greater criticism for taking time off school or work for medical appointments.<sup>36</sup> Women were reported to have more pain and fatigue,<sup>34</sup> worse functional status<sup>18,34</sup> and worse QoL,<sup>18</sup> especially in the *DLQI* and *EQ-5D*.<sup>37</sup> In terms of disability, women experienced more severe family, social, and total disability compared to men. Additionally, they were found to have more frequent premature discontinuation of advanced therapy due to a lack of effectiveness or adverse events<sup>34</sup>. In terms of psychological outcomes, women were more likely to report anxiety or depression compared to men and may have higher psychological burden.<sup>37</sup>

## Mental Health

PsD is associated with profound psychosocial comorbidity due to its chronicity and visibility. Up to 1 in 4 PsO patients suffer major psychosocial distress,<sup>38</sup> but prevalence of depression and anxiety vary in the literature depending on location and population. In a study in Brazil with 497 patients, 20% of PsO patients and nearly 30% of PsA patients reported having anxiety and depression.<sup>12</sup> However, a larger study with 887 patients from 8 countries found that up to 70% of individuals with PsA experienced moderate to major impacts on their mental health as a result of their condition.<sup>8</sup> More than half endorsed that PsA impacted their romantic relationships, with nearly 45% reporting that the disease had negative impacts on their relationships with family and friends. One third of individuals indicated that they had experienced social shaming over their condition.<sup>12</sup> Patients with PsO also demonstrate high levels of alcohol use, alcoholism, and death attributable to alcohol when compared to those with PsO.<sup>38</sup>

The impact of PsD on mental health outcomes vary by patient population. According to Molaei and colleagues who enrolled 558 PsO patients in their study, females were found to be 70% more likely to report anxiety or depression than males.<sup>37</sup> The incidence of depression and suicidality was found to be higher in patients with severe psoriasis compared to mild psoriasis.<sup>36,39</sup> In particular, young patients have a higher risk of suicidality, which encompasses suicidal ideation, attempts, or completed suicide.<sup>39</sup> Young adults between 18–30 years old are the most impacted age category of patients due to stigmatization, which is likely to determine the development of depression.<sup>35</sup> Additionally, patients with early onset psoriasis are also more likely to have certain personality traits, such as greater difficulties with the expression and assertion of anger; this may result in increased vulnerability to PsO-related stresses, especially from social stigma.<sup>40</sup> Successful treatment of PsO was helpful in decreasing rates of depression and suicidality.<sup>39</sup>

Other psychosocial impacts of PsD include negative effects on self-image. Men and women are equally affected by the impact of the disease on appearance and socialization.<sup>29</sup> In a qualitative study by Narayanan and colleagues that interviewed 50 patients with moderate-to-severe PsO, patients described their appearance with “disgust” and “self-loathing” and attempted to hide their symptoms by socially isolating or wearing long-sleeved clothing.<sup>41</sup> Similarly, a survey of PsO patients in the UK reported that up to 80% of participants were too embarrassed to go to the beach or swimming pool, 77% said PsO gave them a feeling of lack of self-confidence, and 79% felt that the condition caused them emotional distress.<sup>42</sup> Patients’ feelings about themselves varied depending on whether they were biologic naïve, were newly initiated on biologics, or were established biologic users. In the same qualitative study by Narayanan and colleagues, biologic naïve patients were found to have the strongest feelings of self-loathing along with higher levels of anxiety about the efficacy of biologics and their side effects. Newly initiated patients continued to fear that their symptoms would return to their pre-biologic state; in contrast, established biologic patients were most appreciative for improvement in their symptoms but had fears over long-term efficacy.<sup>41</sup>

PsD can be socially disabling, resulting from stigma surrounding the disease and patients’ self-image. A lack of awareness of PsO can result in judgements and social discrimination by the general public and even by friends and family.<sup>41</sup> Embarrassment about the disease was found to be highest in young adults between 18–30 years old compared to the 30–50 and the 50+ age groups in a cross-sectional study by Decean and colleagues, which surveyed patients with and without PsO about their attitudes towards the disease.<sup>35</sup> Similarly, an older study by Gupta et al. reported that the age group between 18–45 had more frequent problems related to appearance and socialization, which then declines in the 45+ and 65+ age groups.

This likely reflects that in early adulthood, the social stigma associated with psoriasis has the highest impact as this is when the individual is first establishing their social relationships and entering the workforce.<sup>40</sup> Additionally, disappointment with the inefficacy of treatments can result in worsened self-image and further feelings of social isolation and hopelessness.<sup>5,41</sup> PsD patients may also experience difficulties with sexual activity. A qualitative study that interviewed 20 men and women with moderate-to-severe genital psoriasis reported that patients felt embarrassed or stigmatized to reveal their condition to others in fears that their condition would be mistaken for a sexually transmitted disease.<sup>43</sup>

## Work Productivity, Absenteeism, Presenteeism

Across several studies, it was reported that PsD can impact career choice for those diagnosed from a younger age and PsD symptom flares can impact work productivity.

Thirty-eight percent of participants reported that their career choice and the process of acquiring employment were impacted by their PsD diagnosis.<sup>44</sup> Of the same cohort of 81 patients, 28% reported accommodations including altering job description and responsibilities.<sup>44</sup> Work attendance can be impacted with nearly 20% of individuals with PsD needing to miss one or more full days of work and nearly 30% one or more partial work days in the previous two weeks.<sup>24</sup> While one third of individuals with PsD reported lost work productivity, the mean loss was quite small, with <5% lost productivity being measured.<sup>24</sup> Chan and colleagues estimated a loss of 2.2 hours per week of work due to PsD.<sup>44</sup> Work impairment was another theme in the identified literature. As many as 14% of individuals with PsD reported they worked fewer hours than they desired because of the impact of their PsD.<sup>24</sup>

Work productivity losses were reported to be lower in patients with PsA who are taking biologics and/or disease-modifying anti-rheumatic drugs (DMARDs), suggesting that when individuals taking these medications experience work productivity losses, it is likely due to the high disease severity rather than these therapeutics themselves.<sup>24</sup> This is further supported by the fact that erosive disease (more severe disease leading to breaking down of bone and joints) in patients with PsA is independently associated with workplace-related disability.<sup>24</sup> Education status, self-reported flexibility with working schedule, and self-reported supports within the workplace were all protective factors against lost work productivity.<sup>24</sup>

Sleep disturbance due to psoriasis also had, at minimum “some impact” on performance throughout the day in almost half of all respondents.<sup>32</sup> A study by Husni and colleagues also found that fatigue was a particularly burdensome symptom in PsA patients, where patients with fatigue and PsA missed, on average, more days of work due to short term disability (6.9 days in PsA patients with fatigue vs. 3.4 days in PsA patients without fatigue).<sup>45</sup> Patients with PsO have high rates of comorbidities and in turn, these are also strongly associated with work-loss days. Additionally, indirect work-loss related costs of PsO patients without comorbidities, with 1–2, and 3 or more comorbidities were significantly higher compared to non-PsO patients, even after adjustment for observable baseline characteristics.<sup>46</sup>

The impact on work productivity and activity impairment were greatest in those with higher severity of disease. According to a study by Strober and colleagues, patients in the moderate, severe, or very severe disease categories by body surface area were significantly associated with poorer outcomes in the *Work Productivity and Activity Impairment (WPAI) questionnaire* domains of “impairment while working” and “daily activities impaired”, compared to patients with mild severity.<sup>47</sup> Geographically, the United States had higher proportions of patients who took a sick day compared to Canada; however, more patients in Canada had taken medical leave from work as a result of their disease.<sup>26</sup> The range of absenteeism was similar in both the US (19.3%–22.4%) and the EU (20.8–28.1%).<sup>16</sup>

## Financial Implications

The literature found that PsO severity is correlated with unemployment, income, and income loss.

There appears to be an inverse relationship between PsO severity and income where those with moderate and severe PsO had much lower reported incomes than those with milder PsO.<sup>33</sup> This also extended to employment, with greater unemployment reported amongst those with more severe PsO.<sup>33</sup> The use of biologics increased with income from 4% of individuals in the lowest income bracket taking biologics compared to 14% of individuals with the highest income bracket.<sup>33</sup> This trend of biologic use was highly correlated with income and healthcare insurance coverage.<sup>33</sup>

PsO severity was higher amongst those with lower healthcare insurance coverage, with 43.6% (65/149) of those with severe PsO having full coverage healthcare insurance and 68.4% (13/19) of those with mild disease having full healthcare insurance coverage.<sup>33</sup> The authors posited that this is likely strongly connected to the significantly lower employment and incomes rates among those with severe PsO; 42.2% (8/19) of those with mild disease earned an income in the top quintile compared with only 13.4% (20/149) of those with severe PsO.<sup>33</sup>

Chan et al. reported that individuals with PsO experienced an average \$2,270.84 CAD annual loss of income due to PsO. This would be equivalent to \$3,352.19 CAD [in today's dollar value](#).<sup>44</sup> These findings emphasize the importance of income and disability supports and improved sick-day policies.

## DOMAIN #2: BURDENS ON FAMILIES

Psoriatic disease also imposes a significant burden on families. It is common for patients not to discuss their illness and feelings with family or friends, which can lead to a lack of understanding and support.<sup>11</sup> Through a previous survey, 540 respondents shared their experiences of living with chronic inflammatory diseases. They detailed challenges such as maintaining mobility, managing pain during flare-ups, disruptions to daily life, systemic vulnerability, coping with invisible disabilities, efforts to maintain a positive outlook, and concerns for their families.<sup>20</sup> These challenges illustrate the profound impact of the condition on both the patients and their families, affecting daily routines, emotional well-being, and overall quality of life. The impact on families is an important area for future research, as there are very limited studies reporting on this aspect. Understanding how PsD affects not only patients but also their families could provide insights into additional supports and interventions needed to alleviate this burden. Moreover, despite the broad and detailed search strategy employed in this review, a dearth of evidence on the unique burdens of PsO on families persisted, highlighting the need to focus research efforts on this topic.

## DOMAIN #3: BURDENS ON HEALTHCARE SYSTEMS

In Canada in 2012, the estimated mean annual cost for treating moderate to severe chronic plaque psoriasis was estimated as \$7,966 per patient, with \$4,524 attributed to direct medical and non-medical costs and \$3,442 due to lost productivity.<sup>48</sup> Extrapolated to the national level, this amounts to approximately \$961.3 million annually in direct costs and a total societal cost of around \$1.7 billion.<sup>48</sup>

Annual treatment costs for PsD vary significantly. In one study from 2009, costs per patient ranged from \$19,825 to \$37,600 annually.<sup>49</sup> In a systemic review by King and colleagues which examined the overall economic impact of PsA internationally, the direct costs of PsD ranged annually from €1,261 in Spain to €7,919 in Germany.<sup>50</sup> In a single-center study studying healthcare costs in PsO patients on their first biologic therapy, overall drug costs increased significantly by £9500 ( $P < 0.001$ ) following the initiation of biologic therapy. There was a significant decrease in costs associated with systemic and supportive therapies between the 12 months before and 12 months after the initiation of biologic therapy, which contributed a cost offset of approximately £1000 against the additional cost of biologic drug therapy.<sup>51</sup> Overall, there was a significant increase in mean cost per patient of £7774 in the 12 months after biologic therapy initiation.<sup>51</sup> In another study examining calcipotriol vs. dithranol treatment, dithranol treatment tended to result in increased monthly expenditure ( $P = 0.08$ ), primarily on purchasing new clothing ( $P = 0.03$ ) and new bed-linen/towels ( $P = 0.06$ ) compared to calcipotriol.<sup>52</sup> Interestingly, the availability of full medical coverage in Canada varied inversely with disease severity, ranging from 43.6% with full coverage among those with severe psoriasis to 68.4% among those with mild disease.<sup>33</sup>

Comorbidities associated with PsD significantly increase healthcare costs and resource utilization. People with PsO often have higher rates of comorbidities, leading to more frequent medical consultations, increased medication use, and higher overall healthcare expenses.<sup>46,53</sup> For instance, people with PsA and fatigue incurred significantly higher healthcare costs compared to controls, with notable differences in inpatient, outpatient, and pharmacy costs.<sup>12,54,55</sup>

Biologic treatments, though initially expensive, have demonstrated cost-effectiveness over time by reducing healthcare resource utilization. For example, the average annual cost for biologic treatments in PsO was \$19,026, with higher expenses typically incurred in the first year.<sup>53</sup> The introduction of biologic therapies has notably decreased the need for inpatient care, with hospital admissions for PsO dropping significantly from 120 in 2002 to 2003 to 11 in 2007 to 2008.<sup>56</sup> These therapies not only reduce the number of hospital admissions but also shorten the length of hospital stays, further decreasing overall healthcare costs.<sup>56</sup>

Biologics have shown promise in reducing healthcare resource utilization and associated costs.<sup>57</sup> These treatments have been linked to improved work productivity and decreased healthcare resource use within three months of initiation, with sustained benefits up to 12 months.<sup>57</sup>

## DOMAIN #4: BURDENS ON SOCIETY

The societal cost of lost productivity must be examined when considering the burden of PsD. The cumulative estimated loss of income due to PsO was reported as \$749 million CAD annually which would be more than \$1.1 billion CAD [today](#), indicating that lost work productivity due to PsO not only impacts individuals with PsO, but it has serious implications for the broader economy and society as well.<sup>44</sup>

## Other Resources

While not part of the formal search strategy for the scoping review, several pieces of grey literature that speak to PsD burden are summarized below to add further insights and context to this preliminary report.

[Working It Out](#) is a collaboration between the Canadian Psoriasis Network (CPN), the Canadian Association of Psoriasis Patients (CAPP), and Unmasking Psoriasis. In 2021, Working It Out released findings from Working It Out: A Report on the Experiences of People with Psoriatic Disease in the Canadian Workplace which concluded that individuals with PsD needed more support navigating their disease and necessary accommodations in the workplace.<sup>58</sup> Phase 2 of the project was released in 2022, and included a white paper that analyzed federal public employment and disability policies that affected individuals living with PsD.<sup>58</sup>

[The Journey to Stability Survey](#) is a collaboration between CPN and CAPP focused on understanding the lived experiences of people with PsD and as they manage their disease. This report found that the top five attributes most affected by PsD reported by patients were: lack of self-esteem; interrupted sleep; anxiety; depression; and avoidance of intimacy. These findings are in keeping with several themes identified in our review to date.

[Baring it All](#) is a collaboration between CPN, CAPP, the Canadian Spondyloarthritis Association and the Canadian Arthritis Patient Alliance focused on understanding the experiences and sexual and reproductive health needs of women+ who live with inflammatory arthritis, rheumatic, and psoriatic diseases.

[Optimizing care for patients with pustular psoriasis. Research Report and Summary from National Policy Roundtable \(September 2022\)](#) explores generalized pustular psoriasis, a rare, chronic form of psoriasis and its nuanced challenges including the potential for severely diminished quality of life, reduced productivity, stigma, and risk of shortened life expectancy from disease.

## Conclusions

It is apparent from this report that PsD poses significant burdens to patients and to broader society. This report reiterates concerns about the disproportionate burdens faced by groups that have been traditionally marginalized by healthcare systems. Furthermore, there is concern that burdens compound on one another with worsened disease status being connected with lower work productivity and lower income. While worsened disease severity can contribute to these work-related burdens, it is important to explore how this relationship can be bi-directional. For instance, with poorer income comes greater barriers to accessing care, medicines, and other treatments and supports, which in turn leads to worsened disease progression.

In the next iteration of this report, it will be important to explore how PsD impacts families and healthcare system to better understand the overall impacts of PsD on society at large. Moreover, while not included in to formal review as it was published after the search was conducted, we acknowledge the recent article by Bhutani and Farberg who aimed to “examine real-world evidence on these characteristics and the associated disease burden as related to economic and quality of life factors.”<sup>59</sup>

The review demonstrated that patients with generalized pustular psoriasis – a severe form of PsD – have, on average, one flare per year, but the majority will still experience challenging residual effects after the acute stage of the flare has resolved. This review compliments our work and reiterates the burden PsD poses.

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## About Working It Out

[Working It Out](#) is a collaboration between the [Canadian Psoriasis Network \(CPN\)](#), the [Canadian Association of Psoriasis Patients \(CAPP\)](#), and [Unmasking Psoriasis](#). In 2021, Working It Out released findings from Working It Out: A Report on the Experiences of People with Psoriatic Disease in the Canadian Workplace that concluded that individuals with psoriatic disease were not receiving sufficient accommodations in the workplace.<sup>58</sup> Phase 2 of the project was released in 2022, and included a white paper that analyzed federal public employment and disability policies that affected individuals living with psoriatic disease.<sup>58</sup>

As part of the broader [Working It Out](#) project, which explores the experiences of people with psoriatic disease in the workplace, this preliminary report provides a summary about the burden of psoriatic disease in Canada through the lens of impacts on patients and on the healthcare system. It is intended to be the first iteration of a broader scoping review, which will include the impact of psoriatic disease on other domains such as families and health systems.



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# Appendix 1 MEDLINE Scoping review of burden of psoriatic disease (psoriasis + psoriatic arthritis) in Canada

Search strategies – June 9, 2023

Database: Ovid MEDLINE(R) ALL <1946 to June 08, 2023>

Search Strategy:

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1. exp Psoriasis/
2. (pustulosis or psorias\* or guttate or pustular or erythrodermic).tw,kf.
3. 1 or 2
4. Economics/ or “Costs and Cost Analysis”/ or Economics, Nursing/ or Economics, Medical/ or Economics, Pharmaceutical/ or exp Economics, Hospital/ or Economics, Dental/ or exp “Fees and Charges”/ or exp Budgets/ or ec.fs.
5. (budget\* or economic\* or cost or costs or costly or costing or price or prices or pricing or pharmaco-economic\* or pharmaco-economic\* or expenditure or expenditures or expense or expenses or financial or finance or finances or financed).ti,kf.
6. (economic\* or cost or costs or costly or costing or price or prices or pricing or pharmaco-economic\* or pharmaco-economic\* or expenditure or expenditures or expense or expenses or financial or finance or finances or financed).ab. /freq=2
7. (cost\* adj2 (effective\* or utilit\* or benefit\* or minimi\* or analy\* or outcome or outcomes)).ab,kf.
8. (value adj2 (money or monetary)).ti,ab,kf.
9. (markov or monte carlo).ti,ab,kf.
10. exp models, economic/ or markov chains/ or monte carlo method/ or economic model\*.ab,kf.
11. (“burden adj2 disease\*” or disease cost\* or illness burden\* or BOD).tw,kf.
12. exp “Cost of Illness”/
13. exp Quality of Life/ or “Value of Life”/ or exp \*health status indicators/
14. (“quality of Life” or QOL or qaly or daly or HRQOL or “psychological Well-Being” or SF-36 or SF36 or SF6 or SF-6 or SF8 or SF-8 or SF12 or SF-12 or SF20 or SF-20 or Newcastle or hql or hqol or h qol or hrqol or hr qol or pqol or qls or eq or euroqol or euro qol or eq5d or eq 5d or euroqual or euro qual or “nottingham health profile” or “duke health profile” or “sickness impact profile” or “disability adjusted life” or “willingness to pay” or “functional status questionnaire” or “dartmouth coop functional health assessment\*”).tw,kf.
15. (((social adj2 cost\*) or societal) adj2 cost\*).tw,kf.

16. or/4-15

17. 3 and 16

18. 17 or (burden adj4 psorias\*).tw,kf.

19. exp Canada/ or (canadian\* or canada\* or canadien\* or british columbia\* or vancouver\* or (Victoria\* not Australia\*) or alberta\* or calgary\* or edmonton\* or saskatchewan\* or regina\* or saskatoon\* or manitoba\* or winnipeg\* or ontario\* or toronto\* or ottawa\* or McMaster or thunder bay\* or London Health Science\* or University of Western Ontario or Western University or (Queen\* adj University) or quebec\* or montreal\* or McGill or new brunswick\* or Moncton\* or Fredericton\* or prince edward island\* or Charlottetown\* or nova scotia\* or Halifax\* or Dalhousie or labrador\* or newfoundland\* or ((St or Saint) adj John\*) or memorial university or nunavut\* or Iqaluit\* or northwest territor\* or Yellowknife\* or yukon\* or Whitehorse\* or first nation\* or metis or inuk or innu or autochtone). ti,ab,hw,kf,jw.

20. (canadian\* or canada\* or canadien\* or british columbia\* or vancouver\* or (Victoria\* not Australia\*) or alberta\* or calgary\* or edmonton\* or saskatchewan\* or regina\* or saskatoon\* or manitoba\* or winnipeg\* or ontario\* or toronto\* or ottawa\* or hamilton\* or thunder bay\* or quebec\* or montreal\* or new brunswick\* or Moncton\* or Fredericton\* or prince edward island\* or Charlottetown\* or nova scotia\* or Halifax\* or labrador\* or newfoundland\* or ((St or Saint) adj John\*) or memorial university or nunavut\* or Iqaluit\* or northwest territor\* or Yellowknife\* or yukon\* or Whitehorse\* or first nation\* or metis or inuk or innu or autochtone).ia,in.

21. ((Hamilton not ((Hamilton adj New Zealand) or ((Chedoke or Hamilton or McMaster) adj4 (equation? or index\* or inventor\* or norwood or scale?)))) or (Hamilton adj Ontari\*)).ti,ab,hw,kf,jw.

22. London not (UK or "U.K." or United Kingdom\* or GB or "G.B." or england or britain or british)).ia,in.

23. or/19-22

24. 18 and 23

## About the Canadian Psoriasis Network (CPN)

CPN is a national not-for-profit organization with a mission to enhance the quality of life of people with psoriasis and psoriatic arthritis. We do this in part by providing current information on research and treatment options and by working with others to build awareness and advocacy about the complexity of these conditions.

[www.canadianpsoriasisnetwork.com](http://www.canadianpsoriasisnetwork.com)

## About the Canadian Association of Psoriasis Patients (CAPP)

CAPP is a national not-for-profit organization that was formed to better serve the needs of people living with psoriasis and psoriatic arthritis in Canada. We raise awareness about the burden of psoriatic disease, provide education, support research into psoriatic disease and advocate on behalf of our community.

[www.canadianpsoriasis.ca](http://www.canadianpsoriasis.ca)

## About Unmasking Psoriasis

Unmasking Psoriasis is a Saskatchewan-based awareness group looking to educate employers and the public. We support patients with psoriasis through education and changing the way we think of psoriasis.

[www.unmaskingpsoriasis.org](http://www.unmaskingpsoriasis.org)

Canadian  
Psoriasis  
Network



Réseau  
canadien  
du psoriasis

