PSO SERIOUS 2024:

A Report on Access to Care and Treatment for Psoriatic Disease in Canada

treat psoriasis seriously

Psoriasis Canada

World Psoriasis Day, October 29, 2024

EXECUTIVE SUMMARY

This report represents the third overview of the status of care and treatment of psoriatic disease in Canada over the past decade.

The 2014 Psoriasis Report Card graded the performance of all Canadian jurisdictions in their management of patients with psoriatic disease. This was followed by the <u>Pso Serious 2018</u> report which updated changes to the care and treatment environment for patients with psoriasis over the intervening period. This 2024 report traces developments between 2018 and 2024, referencing both changes in access to dermatologic care in general as well as specific advances relating to psoriatic disease.

Between 2018 and 2024 the number of treatment options available to patients with psoriatic disease have continued to increase and expand beyond new biologics. However, reports published during this period have continued to document the physical and emotional impact of psoriatic disease and its impact on quality of life. Access to timely care for all dermatologic conditions is of increasing concern, even as the COVID-19 pandemic demonstrated the potential for expanding care options to include virtual care.

Based on the findings in this report, some of the key recommendations in the 2018 report continue to be relevant. These include:

- Advocating for a range of treatment on provincial/territorial/federal/private insurance formularies due
 to evolving treatment needs encountered by patients with psoriatic disease over the course of their
 condition.
- Continuing to support medical students to expose them to medical dermatology and encourage them to pursue a career in medical dermatology.
- Increasing awareness of the potential impact of psoriatic diseases on quality of life as well as the classes of treatments and supports available

FORWARD

Over the years, the landscape of psoriatic disease in Canada has undergone remarkable transformations. Most recently, Psoriasis Canada (PsoCan) was created as a single, national, organization that is committed to improving the lives of people with psoriatic disease in Canada.

As the first report of its kind by PsoCan, a consolidation of the Canadian Psoriasis Network and the Canadian Association of Psoriasis Patients, this comprehensive review of the current state of psoriatic disease in Canada is a starting point to drive this renewed commitment.

As we reflect on the state of psoriatic disease since the last PsoSerious report in 2018, we are both motivated by the profound strides that have been made in research, care, treatment, and awareness, and determined to ensure that everyone in Canada can benefit from these gains. Advances in research, innovations in treatment, and a deeper understanding of the disease are paving the way to an increasingly hopeful future for psoriatic disease. We are also witnessing a shift towards a more holistic approach that prioritizes not just physical health, but social, mental, and emotional well-being as well. At the same time, access to care, treatment, supports, and information is not equitable across Canada, stigma persists, and timely access to care and to safe and effective treatments remain out of reach for many individuals and families.

While this report captures a theme of hope for patients, families, caregivers, and healthcare professionals alike, it also gives us a renewed starting point to build on the advancements made and to close the gaps that persist.

As we delve into the findings of this report, we acknowledge the resilience of individuals living with psoriatic disease and the tireless efforts of all those working to support them. It is the collective effort of the community that inspires hope and drives progress.

To us, this report illuminates the possibilities that lie ahead in psoriatic disease and the hope of building a better future together.

Simmie Smith

Chair PsoCan **Christian Boisvert-Huneault**

Christian Botherne met

Vice Chair PsoCan

TABLE OF CONTENTS

EXECUTIVE SUMMARYFORWARD	
	1
Pso Serious 2018 and Beyond: 2018-2024	
Wait Times	5
Family Physicians	7
Dermatology Nurses	٤
Equity	
Diversity and skin of colour	
Virtual Care	
Apps and social media	
ACCESS TO TREATMENT	
Clinical Practice Guidelines	
Topical Therapy	
Systemic Treatments	
-	
3	17
5	
OTHER AREAS OF INTEREST	19
Patient Support Programs	19
Comorbidities	
Psoriatic Arthritis	
Generalized Pustular Psoriasis	22
Pediatric Psoriasis	
CONCLUSION	24
	25
<u> </u>	27

INTRODUCTION

Psoriatic disease is a group of chronic, debilitating conditions that impacts more than one million Canadians of all ages and about 125 million people worldwide. There is currently no cure for the most common forms of psoriatic disease although with current treatments many patients can remain symptom-free for extended periods of time.

Psoriasis is usually characterized by red to violet elevated patches (plaques) depending on the patients underlying skin pigmentation, with overlying flaking silvery scales. Symptoms can range from mild to severe.¹

These signs and symptoms can include:

- Red to violet elevated areas of skin (plaques), usually covered with silvery-white scales
- Scaly plaques on the scalp, or shiny patches on the genitals or in the skin folds
- Itching and skin pain, sometimes severe
- Joint pain, swelling or stiffness in patients who develop psoriatic arthritis
- Nail abnormalities including nail pits, lifting of the nail, or thickening of the nail

While lesions can appear anywhere on the body, the most common sites include elbows, knees, scalp, chest and lower back.

Psoriatic disease can take a variety of forms.

Plaque psoriasis (also known as psoriasis vulgaris) is the most common form, and it occurs in about 90% of patients. It usually begins with red scaly patches and plaques. The symptoms can range from mild to severe, covering very small or extensive areas of the body.

Guttate psoriasis is typically of abrupt onset, appearing in a few weeks, and is often quite extensive. It is marked by small lesions appearing on the trunk, arms, legs or scalp. It makes up about 10% of psoriasis cases and is the second most common form. It can be triggered by an upper respiratory infection, often strep throat. Guttate psoriasis can resolve without treatment, or it can become recurrent throughout life. Not uncommonly, it can develop into chronic plaque psoriasis.

Pustular psoriasis is characterized by pustules (pusfilled bumps) and can sometimes be disabling and, without appropriate intervention in the case of generalized pustular psoriasis, life-threatening due to complications. It can be limited to certain areas of the body (localized) or widespread (generalized).

Inverse psoriasis occurs in skin folds (also called "flexures") where there tends to be pressure, friction and/or moisture or perspiration, such as between buttocks, the genitals, under breasts and armpits. These lesions are smooth and pink or red.

Erythrodermic psoriasis is a rare but serious form of disease marked primarily by widespread redness and inflammation that resembles sunburn. It can result from severe sunburn, use of certain medications (i.e., oral corticosteroids, lithium) or by suddenly stopping systemic psoriasis treatment. It can also stem from poorly controlled psoriasis. It can be life-threatening and usually requires hospitalization since the skin loses its ability to perform vital functions, such as controlling body temperature and protecting against infectious organisms (i.e., bacteria).

Psoriatic Arthritis (PsA): An estimated one third of patients with psoriasis can develop a kind of inflammatory arthritis called psoriatic arthritis. This may be considered its own disease, may be severe and involves inflammation, stiffness and pain within joints (arthritis) in addition to skin plaques. The skin plaques and joint pain may not coincide, so a flare-up may consist of joint pain in the absence of visible lesions or vice-versa. PsA usually develops about a decade after the skin plaques are present.

Unless specifically noted, any references to psoriatic disease in this report will be to plaque psoriasis.

The first large scale-population based study of the prevalence of psoriasis in Canada was published in 2019.² Using health administrative data from Ontario, the study found the prevalence and incidence of psoriasis was similar to those observed in Europe and the US, with a prevalence of 2.45% and incidence of 69.9 per 100,000 population. The authors concluded a steady increase in the prevalence of psoriasis over the past decade "may be due to a combination of population aging, population growth and increasing life expectancy."

Psoriatic disease is associated with several other conditions or diseases including cardiovascular disease, metabolic syndrome, depression, and obesity. Emerging research suggests that people with psoriasis also have a slightly increased risk of serious infections compared to people without psoriasis.

Psoriatic disease has a genetic basis and about one-third of people with psoriasis have at least one family member with the disease. While the exact cause remains unknown, researchers believe it involves a combination of genetic, environmental and immune system factors. The condition develops when the immune system malfunctions, causing inflammation. White blood cells (T cells) in the immune system are triggered and this sets off the inflammation, which causes skin cells to shed at 10 times the normal rate.

In the past five years, knowledge about the genetic aspects of psoriatic disease has increased significantly. The number of genes associated with psoriasis has grown from two in 2008 to 64 in 2017 and recent meta-analysis of all published studies has now identified 109 genes associated with susceptibility to psoriasis.³

Speaking at the 7th World Psoriasis and Psoriatic Arthritis Conference in Stockholm in June 2024, Dr. Wilson Liao, professor and vice chair of research in dermatology at the University of California, San Francisco said genetic research is allowing for a better understanding of which conditions or environmental factors contribute to psoriatic disease.

He said a genetic research tool known as Mendelian randomization has shown that having obesity, Crohn's disease, Type 2 diabetes or depression as well as being a smoker predisposes someone to develop psoriasis whereas Vitamin D intake, fruit intake and educational attainment can be protective. In addition, Dr. Liao said, "genetic factors influence the development of PsA and response to therapy."

Dr. Liao told physicians, "Hopefully not too far in the future you will be able to open up your EMR (electronic medical record) and you'll see a message warning that your patient is at risk of psoriatic arthritis – please screen."

Pso Serious 2018 and Beyond: 2018-2024

Pso Serious 2018: A Report on Access to Care and Treatment for Psoriasis Patients in Canada was published by CAPP in 2018. The report provided an update to the 2014 Psoriasis Report Card on psoriasis care in Canada and a current overview of the status of access to care and treatment.

The report documented the many changes to the care and treatment for people living with psoriasis in Canada in the period between 2014 and 2018. It noted there had been an increase in the availability of data from patients on the impact of psoriasis on overall health and quality of life. The report also highlighted the ongoing lack of awareness of the disease among the general population and medical community in Canada.

The report said that although the number of dermatologists had increased in relation to the Canadian population, many dermatologists report that they are overworked, rural and remote areas of the country are still underserved, and wait times are considerably longer than the five-week benchmark set for non-urgent consultations.

The report identified how the introduction of teledermatology was helping to reduce wait times but was not then well-known or available in all parts of Canada.

In 2018 it was noted that the number of approved treatments of psoriasis had increased by 25 percent in Canada over the previous four years. In the report, many Canadian dermatology experts commented that many more patients could better control their psoriatic disease because of the availability of these new treatments. However, the report also documented how the costs of these biologic therapies were prohibitive for some patients and that not all provinces and territories covered all available treatments.

In 2014, the World Health Organization (WHO) adopted Resolution 67.9 which recognized psoriasis as "a chronic, painful, disfiguring and disabling non-communicable disease, without a cure". As a result of this Resolution, the International Federation of Psoriasis Associations (IFPA) stated, "many national psoriatic disease organizations reached out to their policymakers to demand change."

However, in Canada since the passage of the WHO resolution and the subsequent release of the 2014 and 2018 CAPP reports, and despite advocacy efforts by patient organizations, there have been no national or provincial/territorial initiatives in Canada focused specifically on psoriasis and no initiatives to specifically address the recommendations made in the reports.

That does not mean there has been an absence of Canadian research and publications dealing specifically with many aspects of psoriatic disease and its impact of patients. Some of these new reports have focused on aspects of living with psoriasis, such as intimacy, that have previously gone unacknowledged. A summary of these key reports are included in Appendix A.

Overview

Globally, an Economist Impact white paper⁴ commissioned and supported by Bristol Myers Squibb and published in June 2024 provides a blunt assessment of how much still needs to be done to address psoriatic disease and concerns of patients appropriately. While the overview of how healthcare systems can better meet patients' needs in eight countries does not include Canada, the findings remain very relevant here.

"Despite its widespread impact, psoriasis is misunderstood, under-resourced, underdiagnosed and undertreated. Psoriasis care is held back by knowledge gaps among patients, clinicians and the wider public."

Economist Impact white paper

This paper reviews key aspects of the current state of affairs for psoriatic disease in Canada to help address these ongoing gaps.

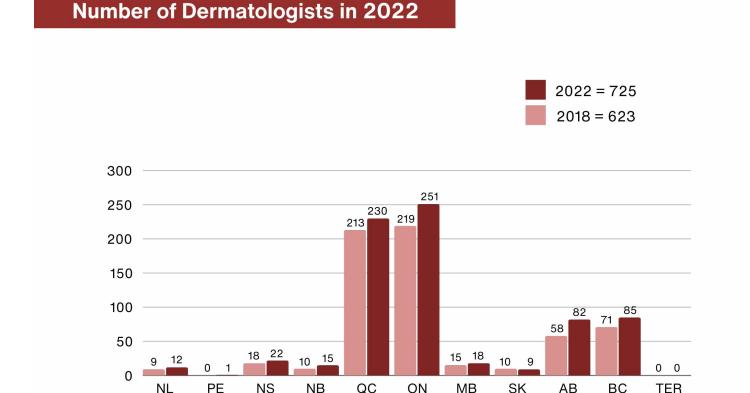
ACCESS TO CARE

"I think that one of the biggest challenges in the Canadian healthcare system ... is always access to care," said Dr. Maxwell Sauder, assistant professor of dermatology at the University of Toronto during a recent podcast.

While this has been particularly true when it comes to access to care from a dermatologist, many residents are now having challenges even finding the services for a family physician to provide primary care. This crisis in primary care is now having a significant impact on timely and appropriate diagnosis and care for those suspected or diagnosed with skin conditions, and psoriatic disease.

While the number of dermatologists relative to the size of Canada's population has continued to increase since 2014, access to these specialists in a timely manner remains problematic in much of the country, especially outside of major urban centres. The issue is not confined to rural and remote areas. Dr. David Adam, president of the Dermatology Association of Ontario notes that he is the only dermatologist in Ajax, a major centre close to Toronto with a population of 131,000.

According to the most current (2022) data from the Canadian Institutes for Health Information (CIHI) there were 725 dermatologists in Canada which represents 1.86 dermatologists per 100,000 population, assuming an even distribution of clinicians. Between 1995 and 2017, this number had vacillated between 1.6 and 1.7 dermatologists per 100,000.



Source: CIHI and CMA

Using data supplied by the Royal College of Physicians and Surgeons of Canada and the Association des médecins spécialistes dermatologues du Québec, the Canadian Dermatology Association (CDA) places the number higher at 770 as of June 23, 2023.

"We're at one dermatologist for 55,500 Canadians roughly," said Dr. Gabriele Weichert, a Nanaimo dermatologist and current president of CDA. "The benchmark, according to the Royal College was that we should have one per 60,000 to 65,000. That benchmark was set in 1998."

In 2017/18, there were 177 Canadian dermatologists in training in Canadian medical schools. In 2020/21, according to the Association of Canadian Faculties of Medicine that number was 189. For this year, the CDA says that number has increased to 191.

However, these general numbers mask huge regional variations in availability of dermatologists and do not reflect the number of dermatologists working specifically in medical dermatology versus cosmetology. This latter issue has become of more concern recently as more dermatologists are focusing on cosmetic dermatology.

"With the cost of running a clinic, dermatologists are leaning into aesthetics more than they had been in previous decades," said Dr. Weichert. "There are fewer dermatologists that want to practice medical dermatology because it's just really hard to pay for your practice," Toronto dermatologist Dr. Geeta Yadav agreed. Inflation has far outstripped increases in physician fees over the last several years. The lack of family doctors is also increasing the complexity of patients seen and introducing problems in ongoing and continuity of care.

Other factors are also impacting the availability of care including the significant number of dermatologists at retirement age or above (19% were 65 years or old in 2022 according to CIHI data). "Dermatologists don't retire quickly, so we have numbers that continue to be counted, but they are not working at the rate that a full-time dermatologist would," says Dr. Weichert.

Dermatologists also share the increasing pressures on the physician workforce in general leading to more burnout and practitioners of all specialties choosing to reduce their workloads or take early retirement.

"I have stories of colleagues who had wished to retire, but just feel so obligated to their patients who have no other opportunity for care."

Dr. Gabriele Weichert

The administrative burden that factors into burnout among physicians has not spared dermatologists. "I do about one to two hours of paperwork a day," said Dr. Ashley Sutherland, assistant professor of dermatology and cutaneous medicine at Dalhousie University "and the vast majority of this involves filling out insurance forms for coverage for our patients on biologics."

"For a multitude of reasons, I think that most dermatologists that are practicing medical dermatology are feeling quite overwhelmed with the burden of patient care," said Dr. Sauder.

With millions of Canadians without a family physician, Dr. Yadav notes dermatologists now often have to become "family physicians of the skin." Without family physicians, she said, dermatologists are making initial diagnosis and treatment decisions that really should be made at the primary care level.

Wait Times

Actual statistics on wait times to see a dermatologist have become increasingly difficult to find since 2018. The most recent comprehensive survey of wait times for dermatologic care was commissioned by the CDA and was published at the beginning of 2019, based on survey responses from 128 dermatologists. This survey found the average wait time for an insured first visit was 20 weeks, while over one in three dermatologists said the wait time is longer than 20 weeks. Insured follow up visits have an average wait time of eight weeks. The published report on the survey findings also noted that "given that nearly seven in 10 respondents say their professional workload has increased in the past 12 months, it's not surprising that six in 10 say they have a longer wait time compared to five years ago."

The CDA was planning to conduct an updated survey of wait times for care and other workforce issues with its membership in the summer of 2024. A 2020 study of primary care clinics in Canada evaluated the period of time between a patient being referred by a primary care physician and the actual visit with the specialist. The wait time to see a dermatologist after referral was 92 days and, in this study, dermatology was one of the most common specialties to which referrals were made.

"The time to get a referral to a dermatologist will vary throughout the country and throughout each province or rural or urban areas," said Christina Craig, a nurse with extensive experience working in dermatology in London, Ontario, in a recent webinar for the CPN. "For example, the dermatologist I currently work for is about an eight to 10 month wait to be seen for non-urgent issues."

"If there are not enough family doctors then what happened is patients will wait three months to see their family doctor, and then they'll wait three months to see me," said Dr. Yadav. "So, they've got six months before they can get seen for potential skin cancer, which is way too long."

What is clear is that the the 2001 benchmark for access to an initial, non-urgent consultation with a dermatologist that was set at five weeks is seen by most as being almost impossible to achieve. "It's very unrealistic, given our current struggles," says Dr. Weichert.

Anecdotally, people in some jurisdictions can wait over a year, if not longer, to see a dermatologist.

In a policy document released in July 2024, the Canadian Medical Association noted a commitment to medically acceptable wait time targets established in the mid-2000s was short-lived and urged leaders "to recommit to create and measure/monitor targets as a catalyst for system improvements."

"I'm deeply concerned about patients who are languishing even on our urgent waitlist. We're not able to provide access. I'm worried about our patients who are not optimizing their employment, or their family situation and having a degraded life quality because of their undiagnosed and managed disease," said Dr. Weichert. Stories in the media have highlighted this crisis in access:

"Linda Lipton was diagnosed with psoriasis almost 20 years ago and the itchiness and burning of her skin has recently gotten worse. Her family doctor referred her to a dermatologist in Moncton and when she called, she said she was told unless she has some form of skin cancer the wait time would be four years. She was also told that wait time is the same for all dermatologists in the province."

CTV New Atlantic, July 5, 2022

"Wait times for dermatology referrals — for conditions from hair loss to rashes to potentially cancerous moles — have risen to the point that some patients in Toronto and beyond would sooner stand in line at 5:30 a.m. to be seen that morning than wait months for an appointment."

CBC Radio, Oct. 28, 2023

Overwhelming demand has caused the Saskatoon Dermatology Centre to close its doors to non-urgent patients. "We currently have about 3,000 patients on our waitlist," Dr. Kyle Cullingham said. "Even with seeing up to 30 or 40 patients a day, we are still not able to meet the demand."

Global News, Oct. 20, 2023

"The longest wait list is for dermatology, with 107,100 Quebecers in need of an appointment to see a dermatologist. Of that number, 66,444 have been waiting past the medically acceptable delays."

The Montreal Gazette, Feb. 20, 2024

One of the only sources of current information on wait times for dermatologic care comes from the dermatology department at Dalhousie University, Halifax which has data available up to the end of 2023. Their statistics categorize the need for care into seven categories from emergent to two categories of routine care. While the average wait time for emergency care was 1.4 days, waits for routine care averaged just more than one year. For patients with moderate chronic psoriasis the wait time was 280.1 days. "Our waitlist is absolutely ballooning," said Dr. Sutherland who works at Dalhousie, noting the situation is true of all Atlantic Canada.

No more detailed information on wait-times specific to patients with psoriatic disease in Canada has been published since 2018. In the Psoriasis: Journey to Stability Study, published that year, wait times to see dermatologists were reported by patients to be on average one to three months for 47% of respondents, followed by 20% taking four to six months. A small survey of patients with psoriatic disease conducted by CAPP also in 2018 showed a significant difference in wait times by province, with longer wait times in the smaller provinces.

The current shortage of family doctors is also impacting access to appropriate care. Dr. Sutherland said this has become an even more pressing in skin care than the shortage of dermatologists.

"Our biggest struggle right now is a lack of primary care for patients. It really causes a lot of issues because patients are seeking primary care later in their disease. So, we're typically seeing more severe cases. And if we do start a patient on a treatment, it's much harder to be able to discharge them out of our practice, because they don't have a primary care practitioner to go back to help to maintain that treatment for us. We end up retaining patients a bit longer and not being able to see some more urgent cases."

Dr. Ashley Sutherland

"The lack of good access to primary care is creating delays in care and so when they (patients) do need care, their condition is more complex," said Dr. Weichert. "On the other side of it, when there's a void in (primary) care, my observation is that patients are referred much more quickly. In past years, the primary care physician would have taken a crack at the situation or even dealt with it with success and the patient would never have been referred. I'm seeing patients being referred earlier than ever, for problems that might have been managed at the primary care level in the past and that's creating a huge increase in our waitlist."

Family Physicians

Some family physicians continue to take an interest in offering dermatologic services as the main part of their practice. This "focused interest" in dermatology is not yet recognized as a specific qualification by the College of Family Physicians of Canada (CFPC), but some Canadian doctors have received online training based in other countries so they can offer more dermatologic services.

In Canada, a Primary Care Dermatology Society of Canada was founded in 2016 and dedicated to creating "a wider awareness and appreciation of the benefits of enhanced dermatology education in primary care and the role of family physicians with a special interest in dermatology." The society website lists 57 family physicians with a focus on dermatology.

Another recent trend in Canada has seen pharmacists in some provinces such as Alberta and Ontario given the authority to manage a number of minor skin conditions. As of 2023, Alberta was the only jurisdiction that allows pharmacists to assess and prescribe medication for patients with psoriasis.

While the CDA has an ongoing concern about non-dermatologists offering dermatology services inappropriately, Dr. Weichert said the association now is more supportive of team-based care and looking at how to fill the void created by an inadequate supply of dermatologists.

Dermatology Nurses

Nurses who are qualified to provide dermatologic care continue to be an asset in Canada but, as with the nursing profession in general, their numbers have declined since the COVID-19 pandemic although exact numbers are hard to ascertain.

Speaking on behalf of the Canadian Dermatology Nurses Association, Sandra Walsh said there are 37 dermatology nurses who are members of the association practising from Manitoba east to Newfoundland and there are new nurses gaining certification in dermatology. Not all certified dermatology nurses are members of the association and statistics are not available for nurses in the Western provinces which are not part of the association.

Equity

Not all patients with psoriatic disease have equal access to care and treatment. The Economist Impact report which assessed care for psoriatic disease in several countries notes that "factors such as a patient's location can constrain access to specialist care, as can socioeconomic barriers."

"Barriers related to socioeconomic status are not only demonstrated by the differences in access to care between the public and private healthcare sector, but also play out where local health services are less resourced, as well as among low-income populations," the report continued.

A literature review recently completed for CAPP, CPN and Unmasking Psoriasis found that the impact of psoriatic disease on health-related quality of life was worse for Black, Asian, and Hispanic/Latino individuals than for white individuals regardless of severity of psoriatic disease, the treatment the patient was on, or other sociodemographic variables. "This raises questions about the impact that systemic racism, and other oppressive systems, may play on worsening psoriatic disease burden since racialization appears to have an impact on the burden of psoriatic disease on quality of life even when disease stage/ severity are the same."

A US review published in 2023 in the journal *Dermatologic Clinics* explored health care system factors, social determinants of health, and cultural or societal differences contributing to racial and ethnic disparities in dermatology care. The review concluded that "when comparing economic factors, low socio-economic status (SES) patients with psoriasis had a consistently lower quality of life and lower work productivity compared with high SES individuals without psoriasis. Additionally, non-White patients reported high costs of care as a significant barrier to seeking and receiving treatment."

A 2017 evaluation of 903 newly diagnosed patients with psoriatic disease at 40 dermatology centres in France found that individuals with lower levels of education were more likely to experience greater severity of the disease, according to multivariate analyses. Moreover, patients with lowers SES and lower educational attainment, who had severe psoriasis, had seen fewer physicians and had less frequently received a systemic treatment."9

"The social stigma of psoriasis can be devastating for patients. Thus, social difficulties increase the delay in psoriasis management, and this delay can, by itself, increase social stigma. Consequently, dermatologists need to break this vicious circle."

Study of newly diagnosised patients

Dr. Yadav said in Canada those patients from BIPOC (Black, Indigenous, People of Colour) communities who don't speak either of the country's two official languages should also be viewed as an underserviced population. "I think there's an overlap of the low socioeconomic status, skin of colour and facing a language barrier," she said.

Appropriate dermatologic care for First Nations, Inuit, and Métis patients, especially those in isolated communities, is also an area in which the system has failed to offer equitable access.

"Skin diseases continue to disproportionately affect Indigenous communities in Canada and around the world, "says a briefing note prepared for the 3rd Annual Indigenous Skin Spectrum Summit in 2023.

First held in 2021, the annual Skin Spectrum Summit is dedicated to improving the cultural competence of Canadian healthcare providers and giving practical advice on providing dermatologic care to Indigenous patients. "Health care for Indigenous peoples in Canada and elsewhere remains severely weakened by the legacies of colonialism and marginalization."

Dr. Rachel Asiniwasis, an Indigenous dermatologist who has a practice in Regina but also provides care in rural and remote Indigenous communities in the province, said there are several barriers that contribute to patients in these communities not receiving equitable access to dermatologic care. A recent survey of 50 healthcare practitioners working on the frontlines in rural and Northern Indigenous communities, conducted by Dr. Asiniwasis and others, identified the following barriers: cost of skincare products or other costs associated with treatments; supply and access to basic skin care items; extensive and overwhelming skin care regimens/instructions to manage skin condition; long waiting times to see specialist and/or primary care practitioner; cultural barriers; transportation issues; limited resources in community to meet required follow-up; and socioeconomic and implementation barriers.

Diversity and Skin of Colour

In June 2020 the CDA joined many other medical associations and adopted a Statement on Diversity and Inclusion. "We are not immune to discrimination based on colour of skin," the statement noted and said the association would take the following steps:

- We will educate ourselves to be a part of the solution. Just as continuing medical education is a lifelong pursuit, taking the time to understand issues affecting those of different backgrounds is crucial to our development.
- 2. We commit to promoting diverse representation among committee membership and senior leadership in medical organizations. We recognize that by seeking individuals from varied backgrounds and ethnic groups, we will be able to endorse more reflective and representative organizational policies.

3. We can help amplify the voice of our colleagues and societies with positive messaging on skin of colour. We will encourage our members and colleagues to include a diversity of skin types when we lecture and teach our medical colleagues and when we produce official CDA communications.

Since publication of the statement, Dr Yadav, who has a special interest in skin of colour issues, said there is now more acknowledgement and awareness of the need to address the issue.

Dr. Weichert said the association remains committed to this statement and is continuing to take steps to meet its commitments in this area. "We're working on supporting educational material around skin of color because that's been a huge gap in our educational opportunities," she said. "It goes beyond skin of color of course. We need to make sure that we've got diversity based on your social origin, your sexual orientation, your religion and beyond."

The issue of skin colour is significant for the identification and management of patients with psoriatic disease as three University of Toronto physicians pointed out in a 2020 case series. ¹⁰ The physicians identified three key practice points for clinicians:

- There are key differences in psoriasis in patients with skin of color, including the morphology (form), clinical presentation, treatment, and psychosocial impact.
- Recognition and awareness of these differences may normalize the condition for patients, support them seeking medical attention sooner, and better inform them of all possible treatment options.
- Advocating for further education on these differences in residency training and continuing medical education programs may help physicians make earlier diagnoses and personalize physician-patient conversations.

Another article published by Dr. Yadav and colleagues in 2022 pointed out that "a major challenge for people with psoriasis and skin of colour is having access to care that is compatible with their cultural values and practices."

"People with skin of colour are more likely to be hospitalized for psoriasis, and their access to physicians may differ compared with white individuals," the researchers wrote. "In addition, differences in how psoriasis appears across racial/ethnic groups may hinder diagnosis. Psoriasis treatments that patients with skin of colour receive may differ from those that white individuals receive, and people with skin of colour may be less likely to be properly represented in clinical trials evaluating psoriasis therapies."

Dr. Yadav points out that dermatologists may unintentionally exhibit unconscious bias toward people of colour who may also be newcomers to Canada and who may have difficulty communicating in English or French, or who are "complaining about something that you can't see or diagnose in the same way they can."

"I think it's nice when we do get supported educational opportunities to continue to explore the subtlety of how we can change our behavior to make sure patients with skin of colour receive better care."

"I believe in representing all skin tones and diverse populations on all levels," said Dr. Asiniwasis but she noted that to date reference to Indigenous patients has been "conspicuously absent" in skin of colour discussions.

"Because of the historical, social and legal complexities and injustice that directly stemmed from Canadian policy and law, I think that there is room for engaging our Indigenous patients and communities in the skin of colour movement," she added.

Research into psoriatic disease is also a key area requiring attention as historically studies into new treatments for psoriatic disease have included a lower proportion of non-white participants than any other areas of dermatology. In addition, the Psoriasis Area Severity Index (PASI) – one of the foundational measures to assess treatment success in psoriatic disease has recently been questioned as erythema (redness) with skin of colour may lead to a lower PASI score.

Dr. Vinod Chandran, a Toronto rheumatologist and associate professor who is co-chair of the international Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) said awareness of these research issues involving skin of colour is growing

but changes may take a generation as new clinician researchers are trained to be more aware. Dr. Chandran said Health Canada has said researchers should include a more diverse population when recruiting patients. As for the PASI score, Dr. Chandran acknowledged there are issues but added currently "we don't have another good measure."

"I really do feel that patient advocacy groups and the industry lobby can play a role in in demanding a higher standard from those who set the rules behind how clinical trials are designed to ensure better participation and better representation and therefore better data."

Dr. Geeta Yadav

One significant development occurred in 2022 when Janssen Pharmaceuticals launched VISIBLE, the first-of-its-kind, large-scale prospective clinical study dedicated to people of colour living with moderate to severe plaque and/or scalp psoriasis. ¹⁴ VISIBLE was a randomized Phase 3b multicentre, randomized, double-blind, placebo-controlled trial examining the efficacy and safety of guselkumab in 200 participants in Canada and the US who identified as non-white.

Dr. Yadav noted that Canada "punched above its weight" in the trial by enrolling more patients than in the US and helping to complete the trial six months ahead of schedule.

The issue of appropriately addressing equity, diversity and inclusiveness remains controversial for some. At this year's AAD annual meeting a highly publicized proposal to eliminate the academy's diversity policies because they were doing more harm than good was brought forward but soundly defeated.¹⁵

Virtual Care

The use of teledermatology and providing patient care by virtual means was attracting a growing interest in the dermatology community prior to 2020. However, with the onset of the COVID-19 pandemic in 2020 dermatologists and their patients found themselves forced to use virtual means such as the telephone or video calls to interact.

Once they were no longer required to use virtual means to communicate to reduce the risk of COVID infection, most dermatologists reverted to in-person care. However, many continue to see the benefits of virtual care in selected situations. Other means of teledermatology, such as asynchronous care in which images of the patient are shared by the patient or their health care provider and then reviewed by a dermatologist later, are also still being investigated.

A 2020 analysis of 1077 consults conducted in Alberta through the asynchronous telemedicine platform ConsultDerm – an asynchronous platform in which patient images along with demographic information and history are stored and forwarded by the referring physician through the online platform to await a dermatologist consultant's opinion - showed an average response time of 5.4 days.¹⁶

Dr. Weichert said dermatologists learned very quickly about the limitations of teledermatology or virtual care - "personally, I don't feel that a consultation in teledermatology is appropriate or good for patient care [in all circumstances]." However, she said, virtual care is an excellent tool for patients who require ongoing monitoring. "What a beautiful convenience for patients not to have to take a half day off of work or drive an hour or more to see you."

Dr. Adam said virtual care has "definitely" had an impact on his practice. For his stable patients who he used to see twice a year in person "if someone's remote and has a fair distance to travel, then I'll just do it once a year and I'll do a remote telemedicine check in for the other visit." However, Dr. Adam also said "I did virtual dermatology during COVID and I can tell you that it's not nearly as good as being in-person. A lot of times the diagnosis is not accurate."

A review of the 30-year history of teledermatology between 1993 and 2023 by a group of Italian dermatologists had an essentially positive overview of the technology. These dermatologists noted that "the end of the pandemic has not led to the disappearance of teledermatology, which remains integrated in clinical practice today. Certainly, virtual visits are reduced, but many studies have shown that teledermatology is particularly useful for chronic skin conditions such as psoriasis ..." The review concluded "teledermatology is

a tool that satisfies patients and physicians ...and is a tool that supports the work of specialists but does not replace them."

As a means of addressing the shortage of dermatologists and long wait times for care, virtual care is now being offered by many companies that have entered the Canadian marketplace. However, medical organizations and some experts are concerned this approach is ultimately not beneficial to patients or the system especially when used by companies that charge patients directly and provide only episodic care.

"Some of the more straightforward dermatology is being seen by other types of models and that puts a greater burden on us in terms of our time and how we're remunerated," said Dr. Weichert.

"There is no follow up provided and no further care which to me is not appropriate management for a chronic disease."

Dr. David Adam

Telemedicine also has the potential to aid in the care of patients with psoriatic arthritis by decreasing the time spent on office visits, but as a commentary by three US physicians noted, "challenges in diagnosing PsA without a thorough in-person physical examination by a trained rheumatologist or dermatologist exist." ¹⁸

For Indigenous people living in remote parts of Canada or other countries, "there is growing recognition that teledermatology may offer at least a partial solution to problems of access. However, the lack of infrastructure in many communities makes such initiatives difficult to implement," the Skin Summit briefing note stated. Another report looking at delivering telemedicine services in remote Indigenous communities in Quebec and Australia notes "delivery of teledermatology through culturally considerate services is crucial to mend the mistrust felt by Indigenous people toward mainstream health services." ¹⁹

Apps and Social Media

The growing availability of medical apps focusing on skin conditions and psoriasis specifically have provided another option for patients to help assess their symptoms. However, an evaluation of eight German apps used for psoriatic disease found few used validated instruments to measure disease activity¹⁵ and their quality in general was judged to be "hetereogenous".²⁰

Social media are another area in which modern communications has had a major impact on helping inform and educate patients about their health, including psoriatic disease. However, the COVID-19 pandemic resulted in an explosion of mis- and dis-information which has continued to this day on social media platforms.

Dr. Yadav says she is a strong believer in using social media platforms such as TikTok and YouTube to educate patients about their psoriatic disease. However, she said, the current amount of misinformation about psoriatic disease on these platforms is "unbelievable". "There's so much stuff out there to make people feel really terrible," she said.

"I'm a huge fan of the kind of education that can be done through social media," she said. On Instagram for example, "people respect and understand the authority that dermatologists have. I think it's really important for us to be able to speak expertly about skincare and skin health and that includes skin diseases and how to treat them."

ACCESS TO TREATMENT

Since the 2018 report, the number of new treatments for psoriatic disease in Canada has continued to increase significantly. The Canadian picture has been mirrored in other countries and has led to experts painting a rosy picture of how well psoriatic disease can now be almost totally controlled for many patients.

"Over the past two decades, stunning progress has been made in the treatment of moderate-to severe psoriasis," said Dr. Joel Gelfand, an American dermatologist and epidemiologist at the University of Pennsylvania in Philadelphia and expert in psoriatic disease. Dr. Gelfand made the comment in an editorial published in the *New England Journal of Medicine* in February 2024.²¹

"It's one of the only complex conditions I care for, where I have a lot of choices for care, and we're optimistic that things will get even better," said Dr. Weichert.

"We don't have a cure for psoriasis at this point, but we do have really amazing treatment options for patients that are lifesaving and life changing."

Dr. Ashley Sutherland

Despite advances in treatments, many patients with psoriatic disease continue to be dissatisfied with their care and failure to control their condition long-term. The Economist Impact report quotes a cross-sectional, cross-country survey of psoriasis and/or psoriatic arthritis patients showing that topical medications (75%), oral treatments (66%) and injectable treatment (84%) were all considered burdensome by the majority of patients. The reasons for this dissatisfaction varied depending on the type of treatment. For example, survey respondents found topical treatments to be messy and not lasting long enough and felt injectable treatments might have adverse effects or caused anxiety when preparing for self-injection. In addition, the Psoriasis and Beyond survey found that 59% of participants feel they have no opportunity to talk with their doctor about what they hope to achieve from their treatment. Access to affordable treatments for psoriatic disease also remains an issue for many patients. As CPN wrote in a submission to the Patented Medicine Prices Review Board (PMPRB) in 2020 "psoriatic disease patients often cannot afford medicines that are available in Canada, particularly new treatments.²² Access to innovative medicines in particular, which can put people into full remission of symptoms in many cases, are out of reach for most people who are not enrolled in a private drug plan. For those who do have public or private drug insurance, the copayments and deductibles can be significant."

"If it is out of pocket I do not get it, try it, or utilize it as I cannot afford it."

From Baring It All

Clinical Practice Guidelines

Clinical practice guidelines (CPGs) are sets of statements prepared by experts and intended to optimize patient care. CPGs for Canadian physicians treating patients for plaque psoriasis were published in 2011 and amended in 2016. No new practice guidelines have been published since that time.

However, this does not mean Canadian doctors lack formal guidance on treating psoriatic disease. The American Academy of Dermatology and the National Psoriasis Foundation published a series of new guidelines in 2020-2021 and a variety of European organizations also published practice guidelines for psoriasis over the same time period.

Also, in 2022 an expert group of Canadian dermatologists convened to develop a treat-to-target (T2T) consensus statement for moderate-to-severe psoriasis. ²³ A T2T strategy defines a treatment target (such as remission or low disease activity) and applies tight controls to achieve this.

The Canadian group agreed that defining treatment target is multidimensional and should reflect objective severity measures, as well as clinician and patient-reported outcomes. The approach provided was felt to "provide a clinical framework for defining treatment success, measuring progress toward treatment success, recognizing when treatment modifications are warranted, and recommending treatment optimization strategies."

While clinicians treating psoriatic disease should follow best practices and incorporate the most recent clinical knowledge, it is not clear how consistently CPGs are followed when it comes to managing patients with psoriatic disease at the primary care level. For instance, a 2022 study of 380 providers of psoriatic care in Canada and the US found the majority of primary care physicians (81%) reported sub-optimal knowledge of the current clinical guidelines for the management of psoriasis and 88% were unaware of the efficacy of available treatments.²⁴

A report published by CADTH (now Canada's Drug Agency) found many physicians were continuing to prescribe "older, less effective biologic drugs" for plaque psoriasis and noted "Canadian physician prescribing patterns may also reflect the absence of new clinical treatment guidelines."

Given the extensive resources required to produce a comprehensive set of CPGs, some dermatologists feel a consensus of expert opinion meets the same needs. "We're getting away from guidelines and more to consensus statements, because it's a little easier to do," said Dr. Sauder. "I think that having some sort of standard of how to manage patients is helpful, whether you call it a consensus statement, or a guideline," said Dr. Adam.

A wide range of treatment options exist for psoriatic disease depending on the severity of disease and patient choice.

Topical Therapy

Topical therapies remain a mainstay for treating patients with mild psoriatic disease and as a complementary therapy when needed in more severe disease. A 2023 CAPP's Living with Psoriasis survey of 507 Canadian adults with psoriatic disease found prescription topicals medications were most tried form of treatment with four being the average number of prescription topical treatments tried.

"I think when most people see their health care practitioner, whether it's a family physician or nurse practitioner or even a dermatologist, topical steroids are the stellar mainstay of treatment."

Dr. Ashley Sutherland

"We've used them for a very long time, and they do still work very well. They can range in strength from mild to super potent. We have creams and ointments and lotions and sprays and foams and oils," she added.

An analysis of current treatments for psoriatic disease written by two Korean dermatologists and published in 2023²⁵ noted that "while the focus of biologic therapies has been predominantly on moderate-to-severe psoriasis, the treatment of mild psoriasis continues to rely heavily on localized therapies such as topical corticosteroids, vitamin D analogues, and calcineurin inhibitors."

"While these treatments can effectively control symptoms in many cases," the authors wrote "there is a need for more targeted and effective systemic therapies for patients with mild psoriasis who do not respond adequately to topical treatments."

Patients in the CAPP survey indicated their perspectives on how topical treatments could be improved:

- 88% of those surveyed said they wished there were more effective topical options
- 83% wished topical treatments could be used daily
- 82% wished topical treatments were easier to use

In terms of the most recent developments, since 2023 there has been a major breakthrough with the approval of roflumilast, a selective phosphodiesterase-4 (PDE-4) inhibitor and a nonsteroidal, anti-inflammatory cream used to treat plaque psoriasis including sensitive intertriginous (skin fold) areas like the face, under the breasts, in the groin, or under the arms. "This really is a game changer for psoriasis," said Dr. Adam.

Tapinarof, an aryl hydrocarbon receptor agonist is another option for topical treatment of plaque psoriasis in the US is also destined to be available in Canada soon as it has been submitted to Health Canada for approval. Dr. Adam said these drugs represent a new option for patients.

Phototherapy

Phototherapy continues to be recommended as an effective and inexpensive form of treatment for some patients with psoriatic disease and it can also complement treatment with topical and/or systemic drug therapy. Phototherapy includes psoralen/ultraviolet A (PUVA) and broad and narrowband UVB treatment, with narrowband being used predominately.

However, access to phototherapy clinics is variable across the country and some patients must travel for hours to receive treatment.

"It (phototherapy) is a really difficult thing to add into someone's schedule if they have a job or they're in school. If you're not close to one of these (phototherapy) units, and access varies widely across Canada it's very difficult."

Dr. Ashley Sutherland

Dr. Perla Lansang, assistant professor of dermatology at the University of Toronto who specializes in pediatric and adolescent dermatology said access for children requiring phototherapy is also "very, very poor ... especially because there are a lot of parents who would rather try phototherapy first for their children from a perceived safety perspective."

One option with growing popularity is home phototherapy where patients can treat themselves with specially designed phototherapy units. Bruce Elliot, president of

Solarc Systems Inc, the main supplier of such home units in Canada, says the COVID-19 pandemic caused about a 40% increase in home phototherapy sales as nearly all Canadian clinics closed, leaving patients with few alternatives. He said sales have since declined but are still above pre-COVID levels.

Home phototherapy gained a boost in Canada in 2020 when Ontario Health, based on guidance from the Ontario Health Technology Advisory Committee, recommended publicly funding home narrowband ultraviolet B (UVB) phototherapy as an option for people with photo responsive skin conditions such as psoriasis. As of the fall of 2024, the Ontario government had yet to act on this recommendation.

Another big breakthrough was when the Lite Treatment Effectiveness Study (LITE) presented at the American Academy of Dermatology annual meeting in the spring of 2024 demonstrated that home phototherapy is non-inferior to office-based phototherapy for the treatment of plaque and guttate psoriasis for all skin types based on assessments by both patients and physicians. The randomized trial involved 783 patients and was a collaboration between the National Psoriasis Foundation, the University of Pennsylvania and the University of Utah.²⁷

Dr. Adam notes even the use of home phototherapy units can be time-consuming and carry health risks but adds phototherapy can be an option for those who do not want to, or cannot, take medication. Most home phototherapy units have four to eight bulbs and this means exposure times have to be very lengthy.

Overall, Elliot said evidence suggests the numbers of phototherapy clinics in Ontario and Quebec appear to be continuing to decline, due in part to the poor remuneration for offering the service. In British Columbia and Alberta, where the fees for offering clinical phototherapy treatment are much higher, he said, new clinics are opening.

Systemic Treatments

Janus kinas (JAK) inhibitors are the newest class of systemic treatments that target specific inflammatory pathways that fuel diseases like psoriasis and psoriatic arthritis. Upadacitinib and tofacitinib are approved for use for psoriatic arthritis. In 2022, Health Canada approved the first tyrosine kinase 2 (TYK2) inhibitor — deucravacitinib — as a new oral treatment for patients with moderate to severe plaque psoriasis.²⁸

Methotrexate, acitretin and cyclosporine remain as options for systemic management of psoriasis either alone or in combination with other agents. These medications "are only a so-so treatment for skin psoriasis, so we don't love them," said Dr. Sutherland. "The flip side is a lot of our private and provincial drug plans will require you to have tried and failed or have a contraindication to one of these medications, before you can apply for access to one of our newer biologic medications. It is a bit of a hoop to jump through and most people will have to try these for at least a short amount of time to see if it has an effect. Then typically, we'll have access to move on to our biologic medications."

Biologics and Biosimilars

The most significant development in the management of psoriatic disease continues to be the development of biologics – agents that block specific components of the immune system such as tumour necrosis factor alpha (TNF alpha), interleukin (IL) 12/23 and, more recently IL -17 and IL -23. Biologics are large molecules manufactured using recombinant DNA technology and are used for the treatment of many other autoimmune diseases such as rheumatoid arthritis and inflammatory bowel disease. Biosimilars are brand name drugs that are similar, but not identical, to existing biologic drugs that have already been authorized for sale. They become available after the patent of the original biologic drug expires and as such, are considered to be more cost effective.

Access to effective biologics remains the biggest addition to the treatment of psoriatic disease, said Dr. Adam even though the first biologics were approved for this indication more than 20 years ago.

In a 2021 review of the use of biologics to treat plaque psoriasis published by CADTH³⁰ (now Canada's Drug Agency) it was noted Health Canada had approved 11 biologics for this indication to that point in time. CADTH divided biologics for plaque psoriasis into two groups based on mechanisms of action and market authorization dates:

- Old-generation biologics (5): include anti-TNF drugs (etanercept, adalimumab, infliximab, and certolizumab pegol) and an anti-IL-12/IL-23 inhibitor (ustekinumab), which were approved in Canada before 2010.
- New-generation biologics (6): include anti–IL-17 inhibitors (secukinumab, ixekizumab, and brodalumab) and anti–IL-23 inhibitors (guselkumab, tildrakizumab, and risankizumab), which were approved in Canada in 2015 or later.

Even though newer biologics are available, CADTH found approximately 44% of patients newly initiating a biologic across public and private drug plans in Canada were prescribed an old-generation biologic in 2020. CADTH noted this was despite newer biologics having "more favourable efficacy" and costing less on an annual basis per new patient.

According to Dr. Sutherland, "It's becoming a bit of an art form to figure out which of these medications is going to be right for our patients in which setting. In the psoriasis world now, we will typically now go primarily to one of the IL-17 or IL-23 biologics as first line therapy..."

Since this report in 2021, Health Canada has also approved the IL-17 inhibitor bimekizumab for the treatment of moderate-to-severe plaque psoriasis and psoriatic arthritis. Bimekizumab has a different mechanism of action compared to the other IL-17 directed biologics because it simultaneously targets two subclasses of IL-17 (IL-17A and IL-17F). In addition, the IL-36 inhibitor spesolimab has also been approved for treatment of generalized pustular psoriasis.

Approval and coverage of biologics benefits patients and dermatologists by providing more options if treatment with one drug fails to work as effectively for any given patient, as can happen over time. A study of 459 patients with moderate to severe plaque psoriasis treated with biologics between 2001 and 2017 found many patients discontinued use of the initially prescribed biologic primarily because of individual treatment failure or side effects.³¹

When it comes to prescribing biologics to treat psoriatic disease, whether reimbursement is through the public system or private insurers, in all Canadian jurisdictions patients must have tried and failed other systemic treatments and/or phototherapy. "If we're going to put on our health economics hat that is the rational way to go," said Dr. Weichert, "and I think a lot of patients are more comfortable with a stepwise approach as well." However, in some cases, she said, the clinician should be able to decide what is best rather than relying on the guideline.

Biologics are the best available therapy (for some patients), said Dr. Adam and this policy raises the question of whether physicians are making decisions "as stewards of the Ontario [public] health budgets or Manulife [insurer] expenditures or are we trying to make the best decision for the patient in front of us."

"I explain to patients that insurers require older meds to be tried before approving newer, more effective ones—not because of safety or effectiveness, but to save money in the short term. As a doctor, I prioritize what's best for my patients' health, so it's frustrating when short-term costs force me to prescribe less effective treatments that can have health and economic implications for my patients."

Dr. Geeta Yadav

Dr. Asiniwasis said the requirement to use systemic immunosuppressants such as cyclosporine or methotrexate that can have serious side effects before treating a patient with a biologic can create particular challenges for those caring for patients in isolated areas who do not have immediate access to care or regular laboratory monitoring. "If something bad happens, the burden falls on the primary prescriber if there's no health practice, which is me," she said.

The requirement to try and fail treatments before being able to access a biologic can also have a negative impact on patients. As CPN wrote in its 2020 submission to PMPRB "waiting to find a treatment that works or hoping that they will be able to access other options if and when their current treatment fails, results in many people with psoriasis feeling like their lives are passing them by as they worry that options may run out and that symptoms may return and/or worsen.

Coverage of Biologics

"There isn't parity across the provinces in terms of how patients access biologics through to the provincial [and territorial] formularies," said Dr. Weichert. "In British Columbia, we're struggling because not all biologics are on the formulary."

Drugs approved for psoriatic disease in Canada can be found here.

Moreover, beginning in 2019, most public drug plans as well as many federal and private plans began expanding the use of biosimilars by implementing biosimilar initiatives. This means that whenever a biosimilar is available in Canada, affected plans will cover the biosimilar version of the drug, rather than its original biologic, with few exceptions.

Initial concerns about the efficacy and safety profiles of biosimilars have died down considerably as studies have confirmed the safety and efficacy of biosimilars. A systematic review of biosimilars used to treat psoriatic disease that was published in 2023 found "there was no clinically or statistically significant difference in efficacy and safety between biosimilars of adalimumab, etanercept, infliximab, ustekinumab, and originators for the treatment of patients with psoriasis." 32

Dr. Adam said physicians who use a lot of biologics in their practice are now very comfortable with using biosimilars whereas the rest of the physician community "is still at the early adopter stage." Starting new patients on a biosimilar is not an issue, said Dr. Adam. It is when it comes to switching a patient from an originator biologic to a biosimilar that the conversation becomes much trickier. He said dermatologists were not really impacted by the first phase of government policies mandating that patients be switched because few biologics they used were involved. However, he predicted that there will be a larger impact with the pending requirement to switch from ustekinumab to its biosimilar.

Research

Canada continues to be acknowledged as one of the world's leading nations for conducting research into psoriatic disease especially in testing new treatments.

"Canada has been at the forefront of research of psoriasis and psoriatic arthritis. We are a country now of only 40 million people but have had an outsized role in all the treatments that have come."

Dr. Vinod Chandran

"Many people outside (Canada) are looking at us to see what we are doing and follow that," he added.

In February 2023 the Skin Investigation Network of Canada (SkIN Canada) published results of a national collaborative exercise to identify the top 10 research priorities for nine key skin conditions.³³ The report of the exercise noted that "reflecting a more mature therapeutic field, questions for psoriasis focused on long term safety and optimizing strategies for existing treatments."

Based on feedback from 71 patients/caregivers and 23 healthcare providers, the following were identified as the top 10 research priorities for psoriasis:

- 1. What molecules and molecular pathways trigger inflammation and lead to different types of psoriasis?
- 2. Does treating psoriasis health improve other conditions (such as psoriatic arthritis, cardiovascular disease, metabolic syndrome and stress) and if so, does treating it early prevent their development entirely?
- 3. What are the long-term risks and benefits of oral and biologic psoriasis treatments?
- 4. What are the molecular mechanisms responsible when treatments stop working?
- 5. Why do psoriasis treatments stop working well against psoriasis, and when they stop working well what is the best way to regain control of the disease?
- 6. Do different genes lead to different type and severity of psoriasis?
- 7. Is a person with psoriasis more likely to develop other health conditions (either as a consequence of psoriasis or due to the effect of treatments for psoriasis)? If so, which ones?
- 8. What is the role of inflammation produced by nerves (neurogenic inflammation) and growth of new blood vessels (angiogenesis) in the development of psoriasis, and can these processes be targeted by new treatments?
- 9. What is the safest and most effective topical treatment for the management of psoriasis?
- 10. How do changes in female hormones, such as during puberty, pregnancy, miscarriage, menopause and contraceptive use, affect psoriasis and its treatment?

OTHER AREAS OF INTEREST

Patient Support Programs

In Canada, patient support programs provided by pharmaceutical companies which began more than 20 years ago continue to support patient access to new medications such as biologics. These programs offer a range of services including navigating the reimbursement process, clinical and nursing support, and patient education.

The Canadian Skin Patient Alliance conducted an online survey in 2019 of patients in Canada formerly or currently taking biologics to better understand their needs and preferences for services and information from these patient support programs.³⁴

The survey involved 50 patients – about half of whom had been prescribed a biologic for psoriasis or psoriatic arthritis. It found that patients required various supports at different stages of their treatment with a biologic.

The report on the survey noted that when first prescribed a biologic, patients "are seeking support to ease them through the unfamiliar application and insurance coverage process at a time when they are often overwhelmed by their diagnosis and disease progression. Patients strongly value services that remove the burden of insurance paperwork, provide them with financial support to pay for their expensive and needed medication, and allow for quick access to the treatment they have been prescribed. Once the patient has begun using a biologic, they place importance on educational services that help them understand the different aspects of their treatment, as well as teach them how to self-administer (if applicable)."

Comorbidities

The commentary published by Dr. Gelfand in the *NEJM* notes that "advances in genetics, immunology, and epidemiology have redefined psoriasis — previously thought to be "just a skin disease" — as a systemic condition associated with obesity, diabetes, major cardiovascular events, and a life expectancy of five years less than that of persons without psoriasis."

Evaluation of almost 2000 Canadian patients with psoriasis enrolled in a global, prospective, longitudinal, disease-based registry – the *Psoriasis Longitudinal Assessment and Registry (PSOLAR)* – found these patients had a variety of comorbidities, including psoriatic arthritis (31.5%), hypertension (34.6%), hyperlipidemia (high cholesterol) (24.3%), mental illness (24.1%), and inflammatory bowel disease (1.6%).³⁵

Having psoriasis may also increase the risk of developing other chronic systemic diseases, including, diabetes, cancer, liver disease and is also associated with obesity. Researchers who conducted the assessment of the Canadian PSOLAR cohort and published their work in 2023 noted "a high proportion of patients in the Canadian PSOLAR population was overweight or obese (84.7%). The impact of this on patient health is significant, as obesity seems to play an important role in linking psoriasis with cardiovascular disease (CVD). "

Dr. Sutherland said Canadian dermatologists are starting to gain a better understanding of the significance of comorbidities associated with psoriatic disease and are starting to make sure patients are screened appropriately for other conditions.

However, this growing awareness of the comorbidities associated with psoriatic disease is not necessary well understood by patients. The global *Psoriasis and Beyond* study found that over 80% of participants were unaware of the increased risk of cardiovascular disease and diabetes associated with psoriatic disease. The survey also found only 29% of respondents were aware of the connection between psoriasis and psoriatic arthritis.

Research into the association between psoriatic disease and mental health is also growing. "Several psychiatric disorders and especially depression have been recognized as comorbidities of psoriatic disease which has been underestimated for a long period of time," said Dr. Wiebke Sondermann, assistant professor of dermatology, University Hospital, Essen, Germany in a lecture at the 7th World Psoriasis and Psoriatic Arthritis Conference in Stockholm in June 2024.

For example, Dr. Sondermann said the prevalence of depression is reported to be up to 33% of patients with psoriatic disease versus 8.1% in the general population in Germany.

While the stigma associated with psoriatic disease often leads to withdrawal that can then lead to depression, Dr. Sondermann said it has now been discovered that chronic low level systemic inflammation can play a role in the development of both psoriatic disease and depression.

She said an increasing number of studies are attempting to evaluate the impact of psychological therapies in managing psoriatic disease with the most promising therapies including cognitive behavioral therapy and mindfulness-based therapies. Dr. Sondermann said while little is known of impact of anti-psoriatic therapies on depressive symptoms in psoriatic disease, in general patients who receive biologic treatment have a reduction in depressive symptoms.

Dr. Sondermann advocated that patients with psoriatic disease with psychiatric comorbidities should receive interdisciplinary care involving mental health professionals.

In Canada, the Collective Group for Psychodermatology has been formed to promote a multidisciplinary approach to mental health issues in patients with skin conditions and facilitate access to psychological/psychiatric resources in dermatologists' offices.

In 2021, the NPF in the US announced it was investing \$1.5 million to test a model to prevent cardiovascular disease and mortality in people living with psoriasis. Dr. Gelfand, who is heading the study said, "If we could improve blood pressure management and cholesterol management, diet, and exercise in people living with

psoriasis, we could substantially improve their well-being, health, and longevity, potentially."36

However, this growing awareness of the comorbidities associated with psoriatic disease have not yet led to more success in managing them. As Dr. Gelfand wrote in his NEJM editorial:

"The progress made with regard to skin clearance in patients with psoriasis is tempered by the relative lack of progress in understanding the effectiveness of these treatments on preventing the development of psoriatic arthritis, diabetes, cardiovascular disease, and premature death — conditions that substantially affect patients with moderate-to-severe psoriasis."

Dr. Joel Gelfand

As the population ages, said Dr. Sauder "we're just going to have an even greater number of patients that are over 65, living with psoriasis," and many of these older patients will have comorbidities. "The management of their psoriasis may be difficult because of a multitude of comorbidities, polypharmacy, adverse events, and also patient hesitation or patient treatment preferences."

Psoriatic Arthritis (PsA)

An estimated 30 per cent of patients with psoriasis will also develop PsA. It is also one of the more challenging types of psoriatic disease to treat because of joint involvement.

Approval of new biologics in recent years have had a huge impact in helping patients manage their disease and possibly even reducing the incidence of the condition.³⁷ However, there is growing acknowledgement that many patients will eventually fail to control their symptoms with any specific biologic.

An analysis of 1,596 Canadian patients treated between 2010 and 2019 found "the proportions of patients who failed to achieve minimal disease activity within six months of an advanced therapy were 64.8% in Ontario, 68.3% in Western Canada, 74.8% in Quebec, and 75% in the Atlantic/East region." European data suggests that in 50% of patients with PsA, a biologic stops working in two years, and every year there is a further drop off.

Dr. Chandran speculated that adjunct treatments such as weight loss drugs may have a future role in helping manage PsA symptoms. Combination treatments involving more than one biologic will also be explored to treat patients with refractory disease.

Dr. Chandran said awareness about psoriatic arthritis has grown in recent years among both family physicians and dermatologists. Dermatologists are now much more likely to ask about joint pain with their psoriasis patients, he said, which means patients with PsA now have less joint damage when they are first diagnosed. However, he said, diagnostic tests such as biomarkers still do not exist to diagnose PsA.

To help assess PsA, Canadian researchers have developed PRESTO, a simple tool that can estimate the 1-year or 5-year risk of developing PsA among individuals with psoriasis.³⁹

Patients with PsA can face even greater challenges in gaining access to specialty care than those with serious plaque psoriasis given that rheumatologists who diagnose and treat the condition can be in shorter supply due to increased workloads. As with dermatology, Dr. Chandran said, timely access can vary widely based on regional differences.

In 2022, the Canadian Rheumatology Association (CRA) issued a position statement noting there were an inadequate number of rheumatologists being trained to meet increasing demands and the large volume of impending retirements among existing rheumatologists. The statement also noted "rural, and remote communities lack access to rheumatologists and face long travel distances to rheumatology care." The CRA proposed a number of steps to address these and other issues, including increasing recruitment and training of new full-time rheumatologists.

"There has been an exponential increase in PsA treatment options over the last 2 decades, and while guidelines have attempted to keep up with the deluge of emerging data, there are several areas in which guidance remains sparse," three researchers from the University of Leeds, UK wrote in a 2024 overview.⁴⁰

In 2021, the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) published updated treatment recommendations for PsA which stressed the need to take a domain-based approach with the treatment of choice dealing with as many domains as possible.⁴¹

With some studies suggesting the use of biologics in patients with plaque psoriasis can prevent the development of PsA, a prospective trial is now underway to test this.

In June 2024, CRA issued a position statement on access to biologics and biosimilars noting they have become the cornerstone to treating many rheumatic diseases including PsA. "As more biologic options become available, including biosimilars, the ability of patients to access different biologic agents or switch between different formulations is important," the statement says. "The CRA encourages rheumatologists to provide the best care for individual patients and be mindful of cost savings for the benefit of society as a whole. When there is a choice available between biologics (including between an originator and biosimilar of the same molecule) then the rheumatologist should consider choosing the most cost-effective option in the context of patient specific factors ..."

One solution implemented to improve care of patients with PsA are clinics where dermatologists and rheumatologists are available to assess and treat patients. The international Psoriasis & Psoriatic Arthritis Clinics Multicenter Advancement Network (PPACMAN) lists three such centres in Canada at the BC Children's Hospital Research Institute, the University of British Columbia, and the University of Toronto. ⁴⁶ Dr. Chandran said it may not always be possible to get a rheumatologist and dermatologist in the same room together to assess a patient, but other options such as virtual care can be used to provide a combined approach to patient management.

Access to rheumatologists remains essential to properly diagnose PsA. As Dr. Chandran noted in a recent webinar "when you look at some patients with psoriasis, about half of them complained of joint pain, but not all of them have psoriatic arthritis. So other musculoskeletal problems like osteoarthritis, tendinitis are also associated with psoriasis. One of the challenges we rheumatologists have is to distinguish the non-inflammatory muscle pain from inflammatory muscle pain because the treatment of that is going to be quite different."

Generalized Pustular Psoriasis

In March 2023, the first treatment for flares in adults with generalized pustular psoriasis (GPP) was approved in Canada. Spesolimab is an injectable novel, selective antibody that blocks activation of the interleukin-36 receptor known to be involved in the pathogenesis of GPP.

As noted in the release⁴² by Boehringer Ingelheim, manufacturer of the drug, GPP is a rare form of psoriatic disease characterized by the sudden appearance of small pustules on large areas of the body. "GPP flares can greatly impact a patient's life and lead to serious, life-threatening complications," said Dr. Hélène Veillete, associate clinical professor and director of dermatology, CHU de Québec-Université Laval and Principal Investigator at Diex Research, in the release.

Approval of spesolimab was based on results of the EFFISAYIL trial, a 12-week Phase II trial investigating 53 patients with a GPP flare randomly assigned to a single 900 mg IV dose of spesolimab or placebo. After one week, 54% of patients with spesolimab showed no visible pustules compared to 6% of patients treated with placebo. After 12 weeks 84.4% of treated patients had no visible pustules.

Spesolimab was discovered and developed while Boehringer Ingelheim researchers were looking more generally for treatments for psoriatic disease, according to a published report sponsored by Boehringer Ingelheim.

"We were initially developing it for the treatment of psoriasis. We weren't focused on GPP, a completely novel disease that we didn't have experience in," said Dr. Carine Boustany, PharmD, PhD, U.S. Research Site Head and Global Head of Immunology and Respiratory Diseases Research at Boehringer Ingelheim. "But when you're committed to the science, it will lead you to the right therapy for the right patient."

A Canadian analysis published in 2023⁴⁴ showed that compared with the most common forms of psoriatic disease, the costs associated with GPP were significantly greater due to the increased number of emergency department (ED) visits or the requirement for inpatient care for patients with extensive cutaneous and/or systemic involvement. Because of study limitations, the

researchers said, the study may actually underestimate the true costs associated with GPP.

Interest in GPP has led the American Academy of Dermatology to launch an initiative involving Al.⁴⁵

The AAD's new Generalized Pustular Psoriasis Education Initiative unveiled at the association's annual meeting in the spring of 2024 aims to transform the care of GPP patients by leveraging the power of data in the Academy's DataDerm dermatology patient registry. According to the ADD, the project will connect the registry's 50 million deidentified patient encounters with OM1's Al-based Patient Finder tool to improve understanding of GPP patients' journey, treatment patterns, disease progression, and outcomes.

Pediatric Psoriasis

As a life-long condition that can have a serious impact on mental health and quality of life, psoriatic disease can be particularly challenging for children and adolescents. Psoriatic disease can present differently in childhood making it more difficult to diagnose – and the shortage of dermatologists currently experienced by adult patients is magnified for those treating pediatric patients.

About one third of patients with psoriatic disease will develop it during the first 20 years of life and it is estimated that 10% of these patients will develop psoriatic disease before the age of 10. Many cases are not properly diagnosed until adulthood.

While most pediatric psoriasis cases are mild and can be managed with topical medications, some children can develop more serious disease, and treatment options are more limited as some biologics not approved for use by younger patients.

"From a numbers perspective there are definitely much fewer pediatric dermatologists than adult dermatologists," said Dr. Lansang, "and there are certain areas in Canada where there are no dermatologists that specialize specifically in pediatric dermatology."

In children, psoriatic disease "often goes unnoticed or undiagnosed," said Dr. Lansang.

"Psoriasis in very young patients can be confused with eczema because they can look very similar. It's very feasible that they've been misdiagnosed in the beginning or just never really got care because it was too mild and parents just thought, "Oh, it's just like dry skin, or just bad dandruff."

Dr. Perla Lansang

Dr. Lansang said there is not yet any research to suggest whether treating psoriatic disease successfully during childhood can prevent more serious disease later in life. But she added "if we can prevent the effects on the quality of lifelong term such as the psychosocial issues, the depression, the loss of productivity, I think that's just as important as getting the disease cured."

As for treatment options in the pediatric population, Dr. Lansang said, "we have more options now than we did, 10 to 20 years ago. But it takes a while to catch up to what's available for the adult population."

For children and adolescents making the transition from pediatric to adult care, Dr. Lansang said the situation can be just as challenging for those with psoriatic disease as for young patients with other chronic conditions. While some dermatologists provide care for both children and adults and can continue to see the same patient this is not true for many patients who then have to face seeing other providers when they become adults.

CONCLUSION

Since 2018, much has changed and much has remained the same when it comes to the treatment and management of psoriatic disease. As this report shows, the understanding of psoriatic disease has continued to evolve and has been accompanied with the availability of exciting new treatment options. The ability of patients with psoriatic disease to control their condition for extended periods of time cannot be understated relative to the situation just 20 years ago.

A better understanding of the genetics of psoriatic disease is opening the door to new opportunities to provide patients with more personalized approaches to their disease. New insights into the association of psoriatic disease with other chronic conditions is leading to approaches which treat the whole patient beyond just their skin or joint conditions.

All these advances have been accompanied by a growing recognition of the need to engage and involve patients in their individual care and in partnering in research and health care policy planning.

Despite these advances it must be acknowledged that many patients with psoriatic disease remain frustrated with the options available to them and the care they receive. Societal attitudes also remain stubbornly difficult to change when it comes to psoriatic disease with stigma against those showing signs of psoriatic disease remaining common.

In addition, ongoing government policies to control health care costs mean many patients with psoriatic disease cannot obtain access to the most effective biologic medications until they have failed to benefit from older and often less effective drugs or phototherapy – which in many parts of the country is increasingly difficult to obtain.

A general deterioration of the Canadian health care system and access to care is now a major factor impacting the ability of patients with psoriatic disease to obtain timely and appropriate care. While the number of dermatologists in Canada continues to increase relative to the size of the population, wait times to see a specialist are often unacceptably long especially in certain regions of the country. Accompanying this has been a crisis in access to primary care which makes it difficult if not impossible for those with suspected psoriatic disease to be assessed and properly diagnosed and treated.

On the positive side there is a growing recognition that these issues must be addressed urgently if Canadians are to continue to benefit from a strong publicly funded health care system.

About Psoriasis Canada

In the spring of 2024, the Canadian Association of Psoriasis Patients (CAPP) and the Canadian Psoriasis Network (CPN) announced that they would be uniting as Psoriasis Canada (PsoCan) to form a single national voice for patients with psoriatic disease in Canada.

Over the past few years, CAPP and CPN have increasingly worked side-by-side to create information, resources, and supports for the psoriatic disease community in Canada, including several collaborations and joint advocacy efforts. Experiences gained during the COVID-19 pandemic further emphasized the value of working even more closely together to maximize capacity and resources.

CAPP was formed in 2012 as a non-profit association with the mission of being a resource to people impacted by psoriasis and psoriatic arthritis by improving their quality of life, raising awareness, providing education, advocating for better access to care and treatments, and supporting research. Similarly, CPN was a national, non-profit organization working to enhance the quality of life of people living with psoriasis and psoriatic arthritis by providing current information on research and treatment options and by working with others to build awareness and advocacy about the complexities of these conditions.

With a new name, brand, operating and governance procedures, PsoCan will be able to scale up its programs, campaigns, and patient support to modernize services and advance advocacy and awareness of psoriatic disease in Canada. A single association provides a stronger voice to address major issues of common interest and better serve the psoriatic disease community.

Our organizations appreciate funding from the Government of Canada's Community Services Recovery Fund to make this process possible.

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Appendix A: Key Reports

In 2021, CAPP and the CPN in conjunction with the Canadian Arthritis Patient Alliance and the Canadian Spondyloarthritis Association published "Baring it All", the final report from a survey of reproductive and sexual health in women+ with psoriatic diseases, inflammatory arthritis and rheumatic diseases.

This first-ever report of its kind in Canada involved more than 400 survey respondents and found that while 63% of participants indicated they can discuss sexual health with their healthcare provider, only 48% indicated they felt comfortable doing so. The survey also identified disparities in information regarding reproductive and sexual health at different stages of life (i.e., contraception, pregnancy, parenting, menopause, etc.); and a general lack of informed discussion or resources regarding the effects of psoriatic disease diagnosis, treatment, and maintenance on reproductive and sexual health, and vice versa.

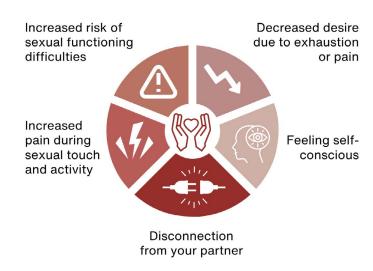
As a result of the survey findings, the sponsoring organizations concluded that:

 Destigmatizing reproductive and sexual health in those identifying as women living with inflammatory arthritis, rheumatic, and psoriatic conditions is critical and recommended that patients, healthcare providers, romantic partners, and support networks raise these topics in conversations about these diseases early and often.

- Patient education resources must be available to those identifying as women with inflammatory arthritis, rheumatic and psoriatic conditions, their care teams, and support networks.
- Rheumatologists and dermatologists should counsel patients about the impact of medications and other treatments on reproductive and sexual health early in their disease journey and regularly to ensure patients can make informed decisions.
- Researchers should consider the sex and gender impacts of access to care, medication safety, mental health, parenting and aging and within racialized communities and the LGBTQ2S+ community to ensure that women+ have the best evidence to inform decision-making.

Also in 2021, CAPP launched the PsoIntimate campaign aimed at tackling issues around psoriasis and intimacy.

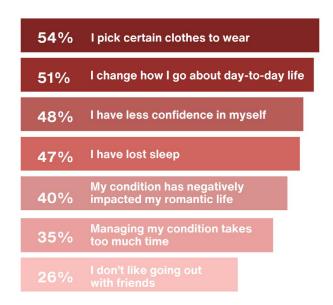
How Psoriasis Can Affect Sex & Intimacy



Source: Intimacy Tips From a Sex Therapist Infographic

A 2022 survey commissioned by the Canadian Psoriasis Network involving 502 patients with psoriatic disease and 307 caregivers showed the ongoing impact of the disease.

Top Impacts of Psoriatic Disease



Source: Canadian Psoriasis Network Information for Healthcare Providers infographic

In 2023, CAPP released results from a national online survey of 507 Canadian adults living with psoriasis. This survey showed the impact of psoriasis on day-to-day life as well as providing insights into patient preferences and gaps in managing the disease.

Despite ongoing educational and advocacy efforts, the survey documented the impact that stigma continues to have on those with psoriatic disease.

- 54% of respondents said they are afraid of how other people will react to their psoriasis
- 50% said they would rather live with a permanent scar than deal with the day-to-day symptoms of psoriasis
- 36% said people around them diminish or minimize their experience with psoriasis
- 28% said they feel people are afraid to get close to them

In January 2024, the US-based National Psoriasis Foundation published a health indicator report also noting the ongoing social stigmatizing beliefs facing those with psoriasis. Based on findings from a 2019 study4 the report showed that among the general population without psoriasis:

- 54.0% would be uncomfortable dating a person with psoriasis
- 39.4% would be uncomfortable shaking hands with a person with psoriasis
- 32.3% would be uncomfortable having a person with psoriasis in their home

The impact of psoriatic disease on patients globally has been documented in the 2021 *Psoriasis and Beyond* survey conducted on behalf of the International Federation of Psoriasis Organizations. The survey involved 4 978 people with a self-reported diagnosis of moderate-to-severe psoriasis in 20 countries, including Canada. The survey found:

- 82% report experiencing stigma and discrimination
- 81% report that the disease has an impact on their relationships

This ongoing stigma continues to be present in the workplace. In 2021, CAPP, the CPN and Unmasking Psoriasis released *Working It Out: A Report on Experiences of People with Psoriatic Disease in the Canadian Workplace*. Based on responses from 190 individuals with psoriasis, more than half of respondents agreed or strongly agreed that:

- Psoriasis or PsA had a negative impact on them at work.
- They felt self-conscious in a way that impacted their performance at work.
- They felt worried to a degree that it had an impact on their job performance.

"This person came up to me and ordered a drink. I mixed it and handed it to him. And he looks at me and says, 'You're contagious, I'm not taking a drink from you." I said, 'It's psoriasis and I'm not contagious." He wouldn't believe me, and he went to management. They let me go that day and I never returned."

From Working It Out

With the outbreak of COVID-19 in 2020, many patients with psoriatic disease had concerns about whether their condition or the immune-modulatory therapies they may be taking made them more vulnerable to infection or prone to more serious outcomes.

Public health agencies did not find those with psoriatic disease were at higher risk for poor outcomes following COVID-19 infection and some studies suggested use of biologics may have been somewhat protective against adverse outcomes¹. Medical and public health agencies all agreed those with psoriatic disease should obtain the COVID-19 vaccine to increase their degree of protection.

The more general impact of COVID-19 on those with psoriasis and PsA was investigated by CAPP, CPN and Unmasking Psoriasis during the first year of the pandemic. In Sept. and Oct. 2020, they commissioned a survey of 830 patients with psoriasis and/or PsA which found that:

- 68% had a virtual medical appointment.
- 57% reported feeling anxiety as a result of the pandemic.
- 45% of respondents had avoided seeking care with a physician or hospital because of COVID-19.
- 40% reported being depressed.
- 25% felt they had worse or much worse access to employment because of the pandemic.
- 13% had to change treatment to manage new flares.
- 10% said their treatment plan was impacted because of the pandemic.

During the pandemic, CAPP and CPN also partnered with other patient and healthcare provider organizations globally on PsoPROTECT, a registry of psoriasis and psoriatic arthritis patients who developed COVID-19. As of the beginning of 2023, 5,400 people had been entered into the registry and observational data resulted in a number of publications.



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