

# Women and Psoriasis: Findings from a Survey of Women with Psoriatic Disease

## Background

Based on a survey of over 100 women-identified people in Canada with psoriasis and psoriatic arthritis, this resource highlights some key findings that can be informational for health care providers who treat and support women-identified people with psoriasis and/or psoriatic arthritis.

### Quick facts

Overall, women experience more severe health-related quality of life challenges compared to men.

- o Survey data from 5,000 patients, showed that 20 percent of women said psoriasis is a very large problem in their everyday lives, compared to 12 percent of men. Nearly 60 percent of women said psoriasis interferes with their capacity to enjoy life, compared to 52 percent of men.<sup>1</sup>
- o A 2018 World Psoriasis Happiness Report<sup>2</sup> finds that women with self-reported psoriasis identify as less happy, more lonely and isolated and more ashamed of their condition than men with psoriasis overall.
- o Women are also more likely to feel an impact of psoriasis on their self-esteem and relationships.<sup>3</sup>

Psoriasis and psoriatic arthritis can also affect family planning decisions, including everything from treatment decisions to lifestyle choices to preparing for the birth of a baby. Yet, one study found that 33% of patients with psoriasis and/or psoriatic arthritis delayed informing their specialist about their pregnancy and 20% did not tell them at all.<sup>4</sup>

Being able to access affordable treatment can be a challenge, especially if a person does not have private health insurance. In fact, 10% of CPN survey respondents indicated that they pay for their medication treatments out-of-pocket and 3% responded that they don't take medications because they cannot afford them.

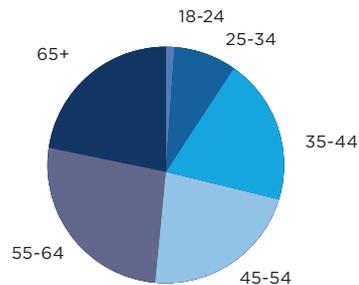
## Survey findings

Overall, the survey results highlight what we already know – that there is no single experience of psoriasis and/or psoriatic arthritis.

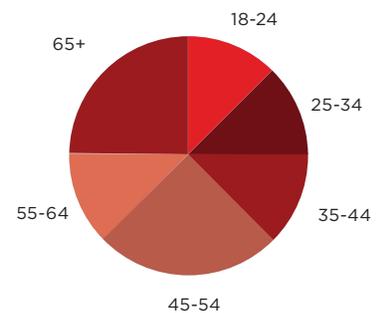
While some women reported severe effects on their self-image and overall well-being, a few indicated that they never had these types of issues. While most women reported that help from health care team members, family and friends and online resources were very useful to them, others shared that they didn't use external resources as a form of support. The effects of psoriasis that different women experienced could be attributed in part to different disease severity/location as well as other personal and social factors.

### Current age

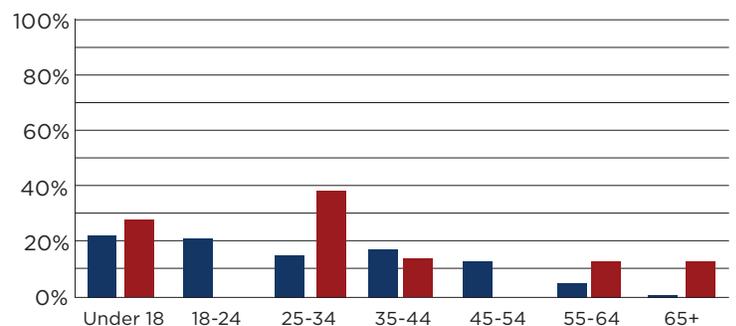
English survey demographics (n=103):



French survey demographics (n=11):



### Age at diagnosis:



■ English  
■ French

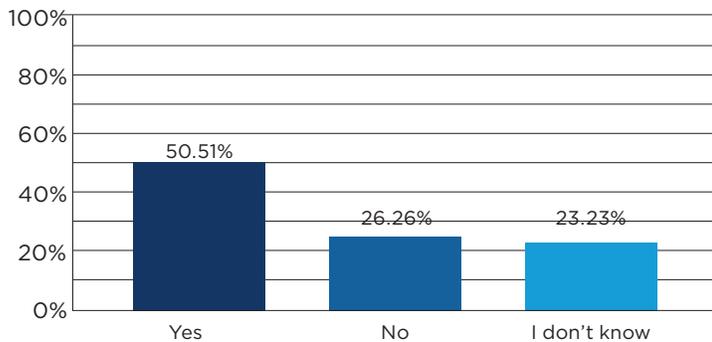
1 National Psoriasis Foundation (NPF). (2015). Women and the heavy toll of psoriasis. Retrieved from <https://www.psoriasis.org/advance/women-and-psoriasis>. Retrieved on Oct 1, 2019.

2 LEO Innovation Lab, The Happiness Research Institute. (2018). World Psoriasis Happiness Report 2018. Retrieved from <https://psoriasis-happiness-report.com/static/documents/world-psoriasis-happiness-report-2018.pdf>. Retrieved on October 1, 2019.

3 Kurizky, PS, & Mota, Licia Maria Henrique da. (2012). Sexual dysfunction in patients with psoriasis and psoriatic arthritis - a systematic review. *Revista Brasileira de Reumatologia*, 52(6), 943-948. <https://dx.doi.org/10.1590/S0482-50042012000600011>

4 Lebwohl, M, Van Vorhees AS, Siegel M, Shankle L, Pisenti L, & Yassine M. A. (2018). Comprehensive survey assessing the family planning needs of women with psoriasis. Poster session presented at The 5th World Psoriasis and Psoriatic Arthritis Conference; 2018 June 27-30; Stockholm, Sweden.

## Just over half had psoriatic arthritis:



## Survey results did point to some overall themes and observations:

- Self-image seems to be a prominent moderate-severe concern over the life span.
- Women identified dealing with severe-to-moderate self-image concerns specifically in adolescence (50%), adulthood (39% severe, 48% moderate) and parenthood (52% moderate).
- Mental health emerged as a moderate issue for respondents during menopause (53%) and adolescence (45%).
- When asked, What was most helpful to you in dealing with any concerns related to stigma, self-image or mental health, the most helpful resources flagged include: dermatologists, social support, internet resources and pharmacists. One's own confidence and internal resources emerged as a theme for women who answered "Other".

## What we heard

### ***Experiences with self-image, stigma and mental health issues***

"I became distant with people, anticipating the fact that I might experience [being unwanted] because of what I have on my skin, it hinders me looking for a job, because of what I feel inside and out, every day is such a struggle."

"Most experiences in public were filled with looks and whispers."

"I feel I was judged and made to feel that this was something I could control. Did not seek another relationship after marriage break up. Every year wished summer was over. Once I was asked to leave a public pool; it was the last time I ever went. I once went to get a mortgage and the person who was helping at the bank wouldn't shake my hand. I have dozens of other instances. Really just putting it down on paper invokes those same feelings..."

"When I had more severe psoriasis on my face I was often asked if it was contagious. I grew my hair out to hide my face."

## What helped

"She [dermatologist] knew immediately how genital psoriasis presents and immediately developed a treatment plan, which has helped. She knew how much pain it was causing me."

"Finding a professional that really understood my issues and did their best to help."

"The doctor tells me that there are a lot of new treatments available. Not to worry when my [treatment] will stop working."

"It's good to not be alone in this aggravation."

"Easy and early - immediate diagnosis."

"It was good to know I wasn't alone and I had felt alone for so long!"

"Someone to listen to me and understand what I was going through!"

"Took me a while for my [doctor] to refer me to specialist. Believe in what you are experiencing and keep telling them. Go back as many times as you have to until they refer you."

"Learning about more natural/lifestyle/dietary ways of helping to deal with my psoriasis."

## How you can help

If you are a prescriber, talk about the pros and cons of different treatment options and supports, including as these pertain to women. Ask about a person's ability to afford these options.

Work with your patients to best support their full range of needs — physical, mental, and emotional — including referring them to other healthcare professionals as needed.

Recognize that many women have questions about diet and lifestyle approaches to psoriasis. Share information and resources accordingly.

Encourage and initiate conversations about family planning and pregnancy.

Recognize the important role you play as a support for a woman who may be struggling with issues related to self-image, stigma and mental health. Connect people living with psoriasis with support, including organizations like ours.

The Canadian Psoriasis Network (CPN) is a national non-profit organization focused on enhancing the quality of life of people with psoriasis and psoriatic arthritis. We do this by providing current information on research and treatment options and by working with others to build awareness and advocacy about the complexity of these conditions.

### Find out more at:

📍 <https://www.canadianpsoriasisnetwork.com/>

🐦 Twitter: @PsoriasisCanada

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