



PSORIASIS
 JOURNEY TO STABILITY
 NATIONAL REPORT
 Canadians' Journey Living with Psoriasis
 Winter 2018





The Canadian Association of Psoriasis Patients (CAPP) is a national non-profit run by a dedicated staff and a committed Board of Directors, who are either psoriasis and/or psoriatic arthritis patients themselves, family members of psoriasis patients, or individuals committed to furthering CAPPs Mission. We are a resource and advocate for psoriatic patients and their families to improve patient care and quality of life.



The Canadian Psoriasis Network (CPN) is a national not-for-profit organization whose focus is on research, education and support for Canadians living with psoriatic disease (psoriasis and psoriatic arthritis).

Our goal is to improve the quality of life of all Canadians who are living with psoriasis and psoriatic arthritis while vigorously pursuing a cure. Our mission is to provide all current information on treatment and continuing care through education, outreach, research and leading by example.



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EXECUTIVE SUMMARY

Psoriasis is a chronic inflammatory condition that affects the regeneration of skin cells. Although technically a skin disease, the impact on people’s quality of life, both physical and emotional, is significant and affects about a million Canadians. The International Federation of Psoriasis Associations (IFPA) reports that there are approximately 125 million affected people worldwide. It is a persistent, chronic condition that may come and go (flare up then go into remission). There is no cure.

The most common form is plaque psoriasis, which affects approximately 90% of patients. Psoriasis can cause as much disability as cancer, diabetes and other major medical diseases. Up to 30% of patients with psoriasis have or will develop psoriatic arthritis and 5-10% may have some functional disability from arthritis of various joints.

Psoriasis impacts every aspect of an individual’s life including their ability to work and maintain social and intimate relationships. In addition to the tremendous medical burden experienced while trying to find a medication that controls the disease, the psychological impact is high. Many individuals suffer from low self-confidence, anxiety, depression and sleep deprivation.

The **Canadian Association of Psoriasis Patients (CAPP)** and the **Canadian Psoriasis Network (CPN)** are not-for-profit organizations each formed to help improve the quality of life of Canadians living with psoriasis. In the fall of 2017, CAPP and CPN collaborated on the development of the **Journey to Stability Survey** with the goal of eliciting a stronger understanding of the patient journey towards achieving skin clearance and stability. In addition, the survey objective was to validate that while every patient’s journey is unique, there are shared experiences and priorities. There are a number of factors that contribute to an individual’s definition of stability. For example, individual coping mechanisms and length of time living with the disease

influences the degree of hopelessness; or hopefulness. Being untreated for a longer period of time, being misdiagnosed or experiencing difficulty accessing a dermatologist are other factors that impact personal definitions of stability. For the purpose of this project, we define stability as an individual’s personal comfort with the effectiveness of treatment and degree of skin clearance and quality of life. While the survey was tailored to Canadian psoriasis patients in order to form a baseline of individuals’ experiences and personal journeys, many aspects of this condition are global in nature.

In Canada, the journey to being well controlled or stable is onerous and involves being prescribed a treatment and often failing on several different medications before finding one that is effective. A considerable number of people surveyed

lived for 10 or more years with uncontrolled/unstable psoriasis before finding a medication that controlled/managed their psoriasis. There are a significant number of people who continue to feel their condition is still not controlled at all or is poorly managed.

Biologics are a newer class of treatment that have been available to Canadian psoriasis patients for over 10 years. Knowledge of biologics and newer biosimilars remains low, with the majority of Canadians classifying themselves as knowing very little or only having “some knowledge” of this class of medications.

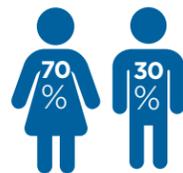
Canadians who are well controlled/stable after a lengthy and emotional journey, reacted strongly in this survey to the possibility of being switched to another medication for non-medicinal reasons. Generally, they feel that any change in medications should be decided by their physician in consultation with them. If made to switch,

many patients fear their mental health would be negatively affected and they would fight to remain on their current medication. The survey results validate the significant and varied impact psoriatic disease has on patients and confirms

there is an unmet need for more treatment options, education and support for Canadian patients. Having access to new and innovative medication is paramount to providing options and hope to patients and healthcare professionals alike.

286
survey responses from individuals living with or affected by psoriasis

Of the respondents, approximately:



Respondents diagnosed with moderate to severe condition 70.63%

Majority of respondents have lived with psoriasis for

20+
years

Majority of respondents were in the age range of:

51-65
years

BACKGROUND

Psoriasis (pronounced so-RYE-a-sis) is a chronic inflammatory condition that affects the regeneration of skin cells. Normal skin cells grow, mature and are shed as part of a natural cycle that takes 28 to 30 days. Psoriasis is a common skin condition that happens when faulty signals in the body’s immune system trigger new skin cells to form in three to four days instead. Because the skin cells grow too quickly, they are not shed normally. Instead, they pile up on the skin’s surface, creating sores or lesions—often called plaques. Thick, silvery scales form atop these itchy and sometimes painful red patches.

Psoriasis usually affects the elbows, knees and scalp, but it can also occur on the palms of the hands, soles of the feet, nails, genitals and torso. Severity of psoriasis varies with each person and can range from a few patches here and there to full body involvement. Assessment is usually discussed in terms of “mild,” “moderate” and “severe”; in psoriasis patients, about 65% of people have mild psoriasis, about 25% have moderate psoriasis and about 10% have severe psoriasis.

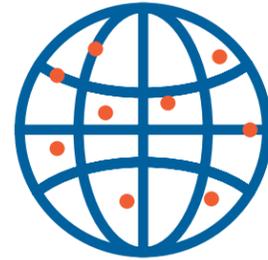
LEVEL OF PSORIASIS SEVERITY DEFINITIONS:

Mild	Moderate	Severe
<p><3% of the body.*</p> <p>Generally involves isolated patches on the knees, elbows, scalp, hands and feet.</p> <p>Typically little effect on the quality of life.</p>	<p>3-10% of the body.*</p> <p>Generally appears on the arms, torso, scalp and other regions.</p> <p>Often results in concern about others’ reaction to visible lesions.</p> <p>Generally affects the quality of life.</p>	<p>>10% of the body.*</p> <p>May affect large areas of skin.</p> <p>Psoriasis of the face and palms/soles may be considered as severe.</p> <p>Typically has a severe impact on the quality of life.</p>

*To assess the area of involvement, consider that your palm covers about 1% of the skin’s surface; the number of palms of your skin involved with psoriasis is a reflection of the body surface involved.

125 million
(or 2-3% of the world's population)
have psoriasis

most common form
plaque
psoriasis
≈ 90% of patients



1 million Canadians

Up to **30%** have or will have arthritis

Severity is also measured by the impact psoriasis can have on a person's quality of life. Psoriasis can have a big impact even if it involves a small percentage of the body.

About one million Canadians' are affected by psoriasis and about 125 million (2-3%) of the world's population has psoriasis. It is a persistent, chronic condition that may come and go (flare up then go into remission). For many it does not go into remission.

The most common form is plaque psoriasis, which affects approximately 90% of patients. Psoriasis can cause as much disability as cancer, diabetes and other major medical diseases. Up to 30% of patients with psoriasis have or will have arthritis. Having psoriasis may increase the risk of developing other chronic systemic diseases, including heart attack and stroke, diabetes, cancer, and liver disease.

Most cases of psoriasis can be controlled, and most people who have psoriasis can live normal lives. However, some people who have psoriasis are so self-conscious and embarrassed about

their appearance that they become depressed and withdrawn. Psoriasis is often more emotionally disabling than physically harmful. In addition to managing the physical effects of psoriasis, many also manage impacts on mental health through pharmacologic treatments, counselling and stress-reduction programs.

The **Canadian Association of Psoriasis Patients (CAPP)** and **Canadian Psoriasis Network (CPN)** surveyed Canadians to better understand what "stability" or being "well controlled" means to Canadians living with moderate to severe psoriasis and the journey they take to becoming "stable" or "well controlled". The findings and insights learned will influence future work conducted by CAPP and CPN to improve the patient journey and outcomes.

This report will provide a baseline comparison as we move forward and track the progress of our healthcare systems in reducing the time to controlled disease management and access to effective care and treatments.

Sources: CAPP, CPN, CDA and IFPA Websites

METHODS

CAPP and CPN developed an online *Journey to Stability Survey* for psoriasis patients. The survey was reviewed and pilot-tested by two executive members of CAPP and CPN, who provided patient perspective, and assisted with revisions for clarity, comprehensiveness and what resonates with individuals living with psoriasis.

SURVEY ELIGIBILITY CRITERIA:

- Be Canadian
- Have a diagnosis of psoriasis
- Be a caregiver/loved one of someone living with psoriasis

The survey was created in *Survey Monkey* and designed to be completed within 20 minutes. The average length taken to complete the survey was 16 minutes.

SURVEY DISSEMINATION:

The electronic survey link was disseminated by CAPP and CPN through various social media platforms (Facebook, Twitter, websites) to access people across Canada. It was also disseminated by the CAPP and CPN electronic newsletters as well as to patients enrolled in the AbbVie Care Support Program.

Respondents were encouraged to share the link with others who may be interested in sharing their experiences and having their voice heard. The *Journey to Stability Survey* was open from September 15, 2017 to November 8, 2017.

“Generally I am a positive person and strong willed but this condition can really bring **you literally to tears.**”

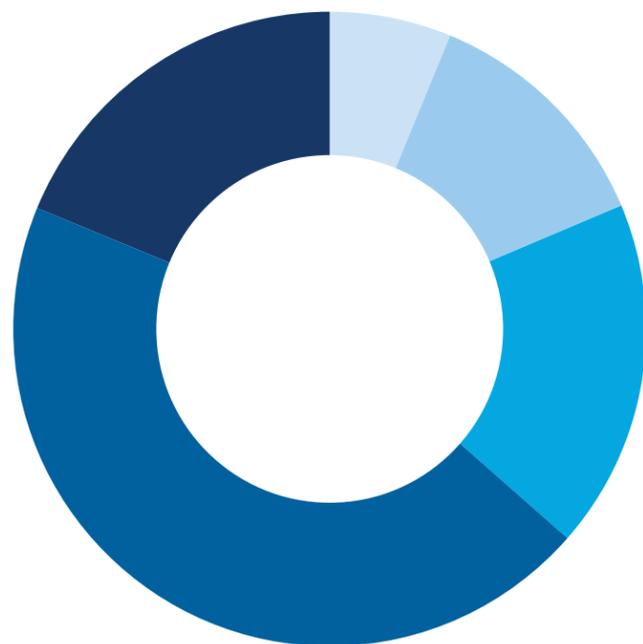
RESULTS

In total, surveys were completed by 286 English respondents (see appendix A for surveys completed in French) with the majority (96.5%) being adults living with psoriasis.

DEMOGRAPHICS

The majority of respondents who provided their demographic information were female (70.4%) and 28.4% were male; 39.5 percent opted to not provide this information. Of the 169 respondents who provided demographic information, the majority of respondents fell between the ages of 51-65 years of age.

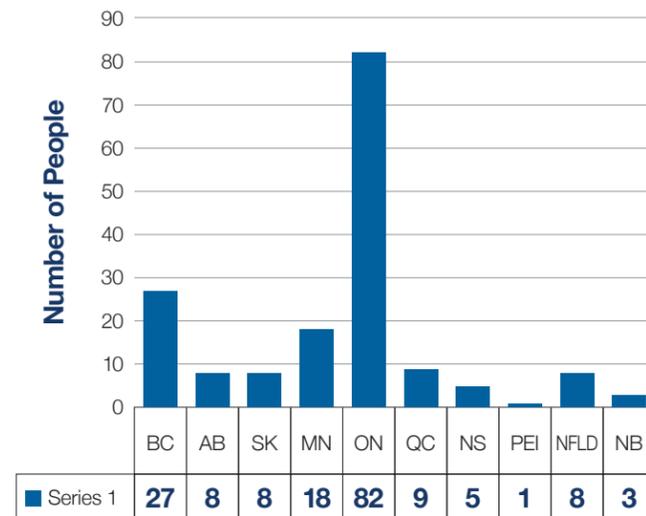
Figure 1: Age of Survey Respondents



- 66 years or older – 19%
- 51 - 65 years – 45%
- 41 - 50 years – 17%
- 26 - 40 years – 13%
- Under 25 – 6%

There was representation from all provinces however the majority reported that they live in Ontario.

Figure 2: Provincial Distribution of Respondents



NOTE: the results of this survey are reflective of how the survey was distributed. There are no current data available that demonstrates the prevalence rates of psoriasis in each province.

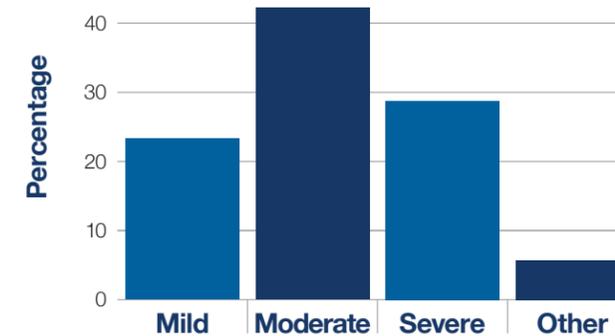
SECTION 1: WHO ARE YOU?

To better understand more about the individuals who participated, the first few questions were asked to provide general knowledge.

Respondents were asked to tell us what best describes their psoriasis (mild, moderate or severe); About 42% described themselves as having moderate psoriasis, 28.67% described themselves as having severe psoriasis and 23.43% described their condition as mild. There were 17 individuals who selected the “other” category who were unsure of how to rate themselves as they were either severe or moderate in the past and are now improved or drift between stages. There were three individuals who identified they were also living with psoriatic arthritis.

Of the comments provided, many complained of “majority” or 50%+ total coverage on the body. These people also identified issues related to their face, scalp, ears and/or fingers being affected.

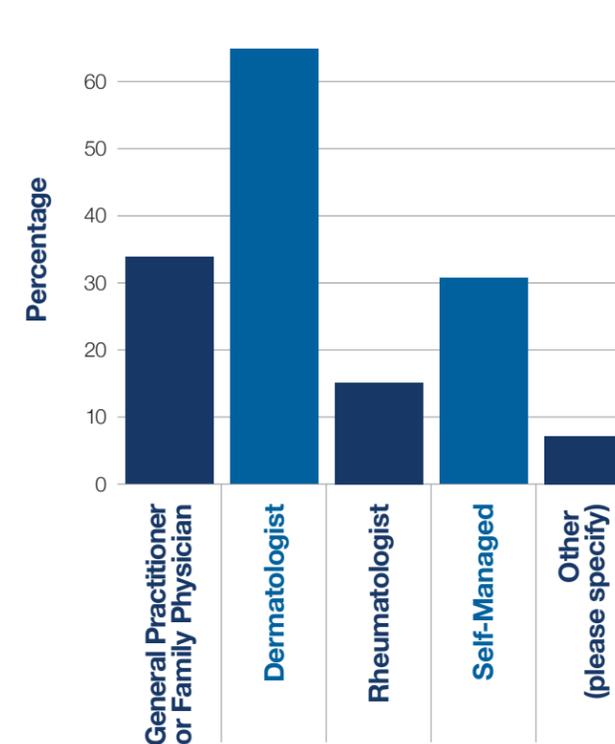
Figure 3: Description of Psoriasis



Respondents were asked to select all that apply with regard to who manages their treatment. The majority of respondents are seen by a dermatologist.

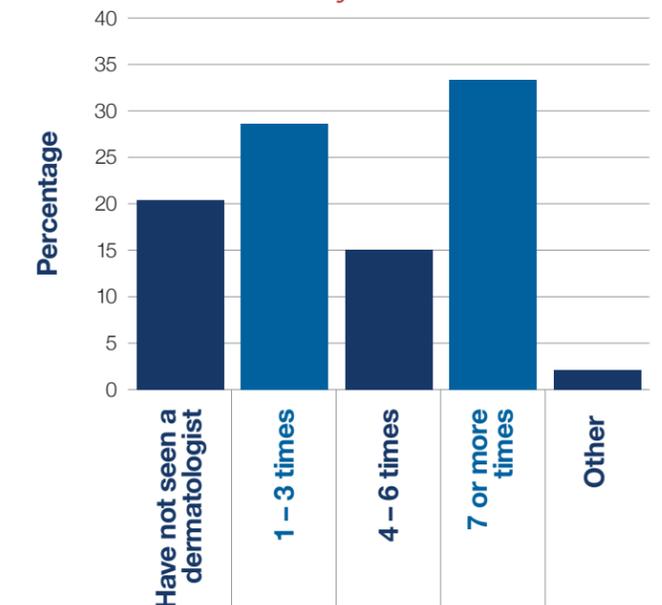
Of those who selected “other”, around 75% were self-controlling the disease (without any medical intervention). The other 25% use a wide variety of doctors and fields of medicine to help manage their condition (such as acupuncture, naturopaths, etc.)

Figure 4: How Treatment is Managed



When asked how many times over the past five years respondents have seen their dermatologist 20.63% have not seen a dermatologist. 33.57% have seen their dermatologist seven or more times which could be interpreted that they are being regularly re-evaluated and medications managed appropriately by their physician. For those who have not seen a dermatologist and provided a reason why, most indicated it was either due to the fact that their family physician would not refer, they were currently waiting for their appointment or there wasn't a dermatologist in their community. For those people who responded using “other”, the general theme seems to be due to a lack of doctors within a reasonable distance. Another underlying theme for these people is that the wait times to get into a dermatologist can be lengthy (6 or more months) supporting the need for more dermatologists in Canada. Some, but not many, are seeing the dermatologist regularly and have been for years.

Figure 5: How Many Times a Dermatologist is Seen Over the last 5 years



“Lack of permanent solution to chronic problem... I do not want to manage I want to be cured.”



Wait times to see dermatologists are on average 1-3 months for 135 of 286 people, followed by 57 or 19.93% taking 4-6 months. For over 13%, it took between 7-18 months. The majority of people who provided feedback find wait times in Canada to be acceptable or indicated that they have not seen a dermatologist and cannot comment. Some additional comments provided included: “GP will not refer me, psoriasis is well controlled and I do not need to see one” and several “have just given up.”

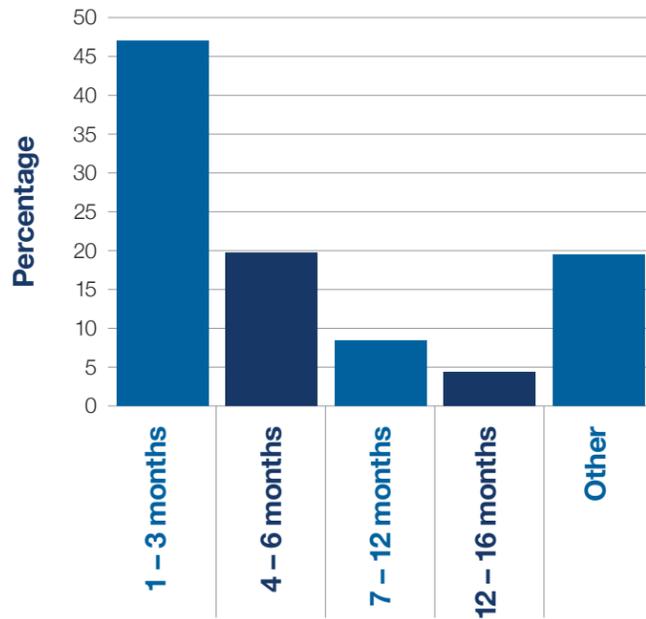


Figure 6: Wait Times to See a Dermatologist

The number of respondents have been living with psoriasis for 10 years or more was over 50%; followed by 19.23% between 10 and 20 years. Only four (1.4%) respondents have been living with psoriasis for less than one year.

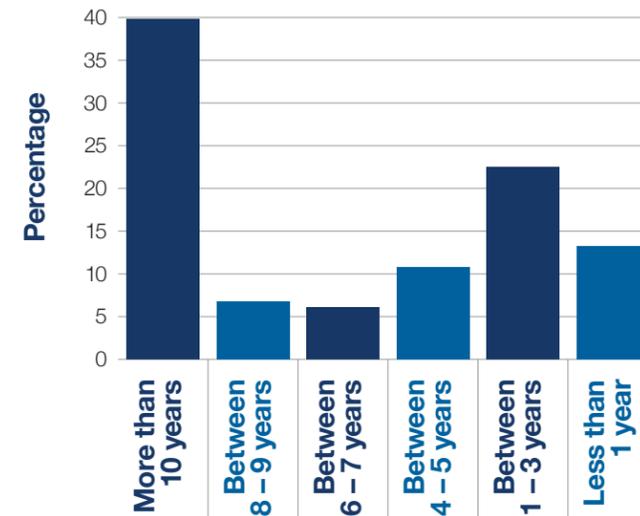


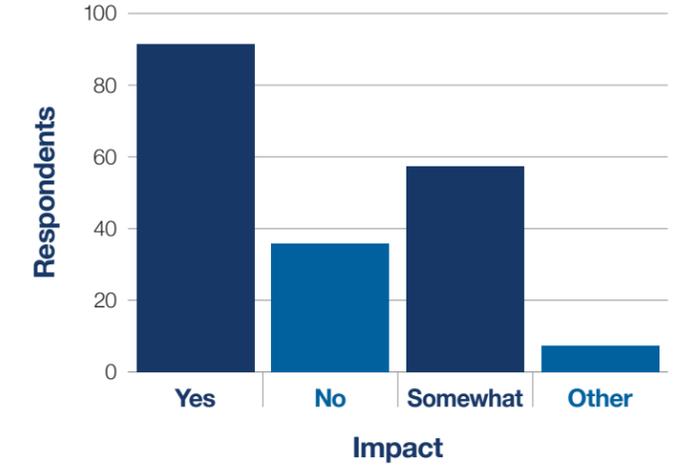
Figure 7: Length of Time Individuals Have Lived With Psoriasis

SECTION 2: QUALITY OF LIFE

The emotional impact of psoriasis on a person’s life does not depend on the severity of the lesions. It is determined by how each person feels about the itchiness, pain and discomfort of psoriasis and the visibility of the lesions.

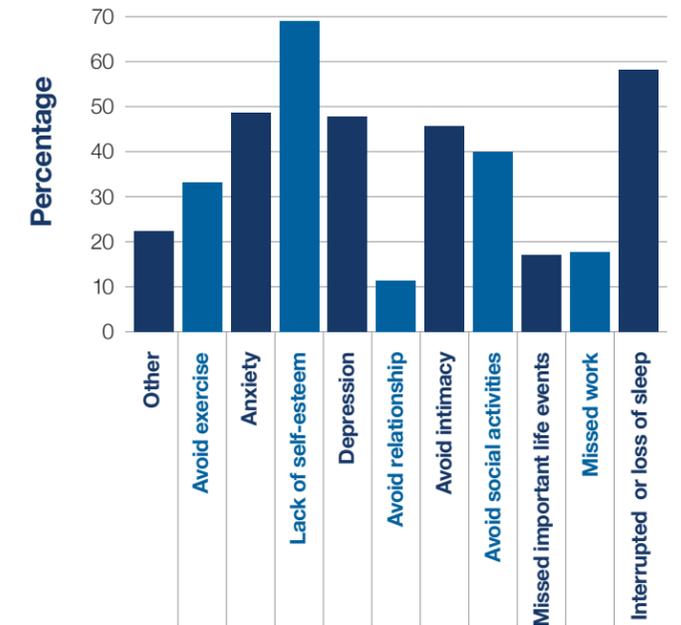
When asked if psoriasis negatively impacts respondents’ lives, only 19.65% indicated that it did not affect their daily lives in any capacity. The remaining 80.35% were negatively affected to some extent. The majority of the 78 comments provided support that individuals are mentally impacted. Pain, itchiness and self-consciousness were common attributes that negatively impact people’s quality of life. There were approximately 10 people who mentioned that their quality of life has improved since their symptoms have become controlled by medication.

Figure 8: Impact on Quality of Life



Respondents were asked to select all the personal attributes experienced over the past few years. An overwhelming 68.91% felt psoriasis contributed to a lack of self-esteem, followed by interrupted or loss of sleep for 58% and 48.7% experiencing anxiety. Additional comments provided were loss of missed job opportunities, limited mobility, cannot swim in public pools, limited choice of clothing that can be worn and embarrassment.

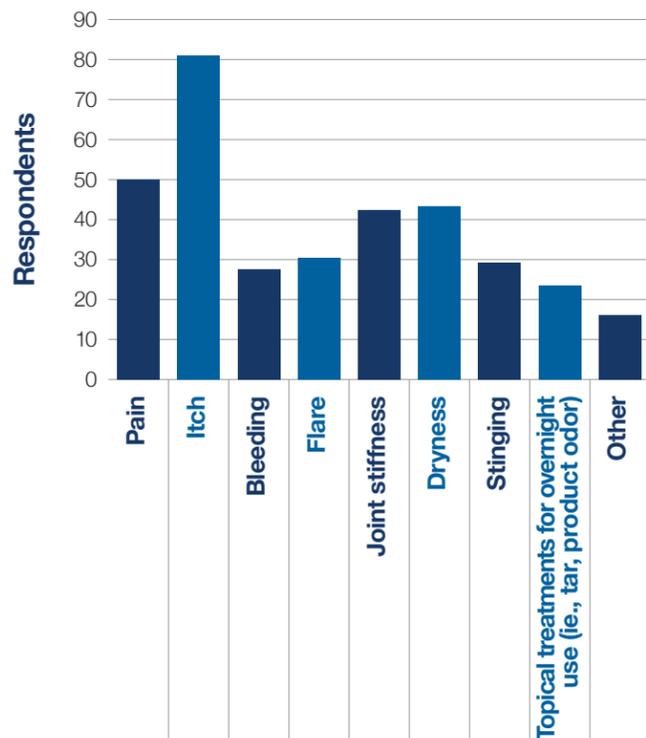
Figure 9: Attributes Affected by Psoriasis



Exploring further, when asked to rank the same attributes in importance, self-esteem and lack of sleep remained the most important and when asked why sleep was interrupted, pain and itchiness were the reasons (50.26% and 81.87%, respectively). The attribute that was ranked first overall in importance was self-esteem, following by interrupted (loss of) sleep while the least important (ranked tenth) was missed work and avoiding exercise.

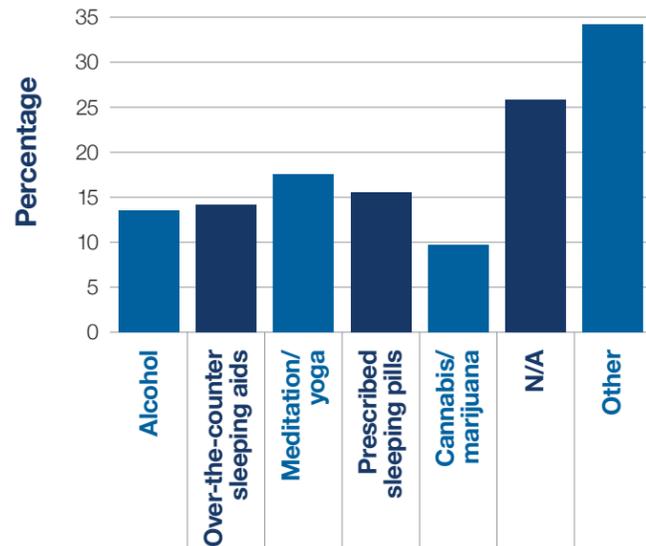
Other comments provided fell into common themes. These comments included difficulty finding a comfortable sleeping position and that the creams and ointments made it difficult to get to sleep due to being oily/sticky and smelly. These problems actually made people focus on the itching more.

Figure 10: Lack of Sleep Attributes



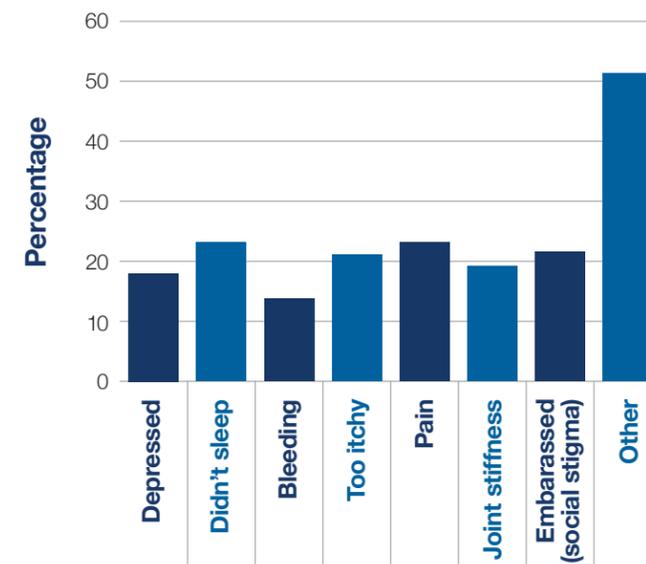
No dominant coping mechanism for lack of, or interrupted sleep emerged however, meditation and yoga were slightly preferred.

Figure 11: Coping Mechanisms for Lack/Loss of Sleep



For individuals not able to work due to their psoriasis, the reasons provided were fairly consistent. Pain and lack of sleep were the most common reasons, with itch and embarrassment close behind. There were 99 comments provided with the majority of respondents saying they have not missed work and many respondents are retired or do not work (reasons not provided). Although the majority of people only missed 1-5 days over a 12 month period, 11.92% missed 6-10 days. There were 4.15% who used 15 or more days and 6.74% of respondents went onto disability. Of the people who selected “other”, the majority of comments for not missing work included: could not afford to miss work, always pushed through it or were retired.

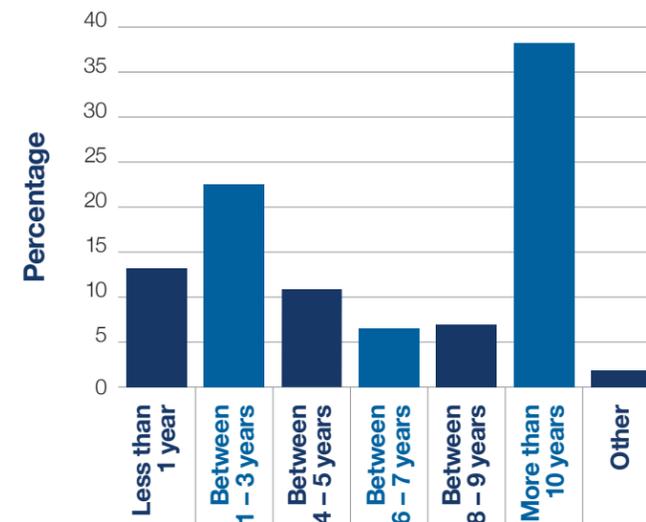
Figure 12: Reasons for Missed Work Days



SECTION 3: JOURNEY TO STABILITY/CONTROLLED PSORIASIS

About 38% of respondents indicated that they felt their condition was not satisfactorily controlled for 10 or more years. There were 13.29% who have lived with their condition uncontrolled or unstable for less than one year. The survey did not identify the reason e.g., disease worsening or newly diagnosed.

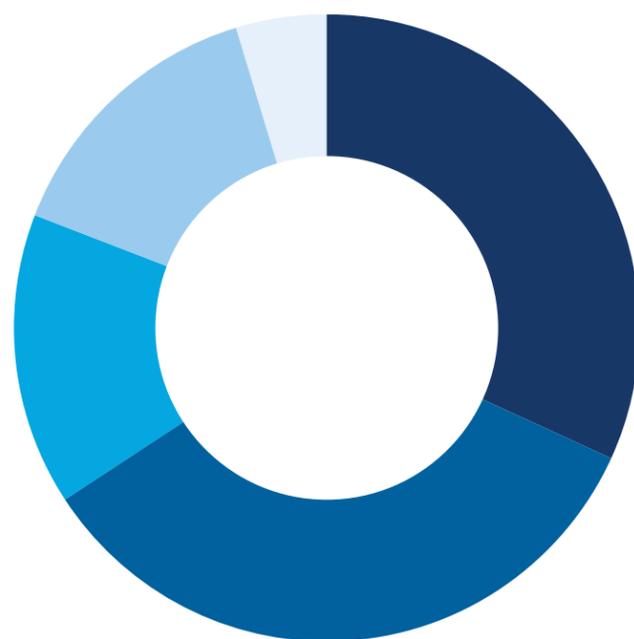
Figure 13: Individuals Living with Uncontrolled/Unstable Disease



“It upsets me all the time which I am sure leads to many other conditions like depression and anxiety. I feel very ashamed of my looks.”

The majority of respondents reflected they experienced their psoriasis being controlled off-and-on and have just learned to deal with it. Some have “given up hope”.

When asked how well the respondents' psoriasis is currently controlled, 34.10% feel their condition is "somewhat controlled" versus 31.79% who feel it is well controlled and 29.48% feel their condition is either not controlled at all or poorly controlled. Of the seven respondents who selected "other", comments were "great now" (3), "just starting treatment" (1) or "drifts in and out of being controlled" (2) and "psoriatic arthritis is poor but psoriasis is controlled".



- Well-controlled
- Somewhat controlled
- Poorly controlled
- Not controlled
- Other

Figure 14: Controlled vs Uncontrolled Condition

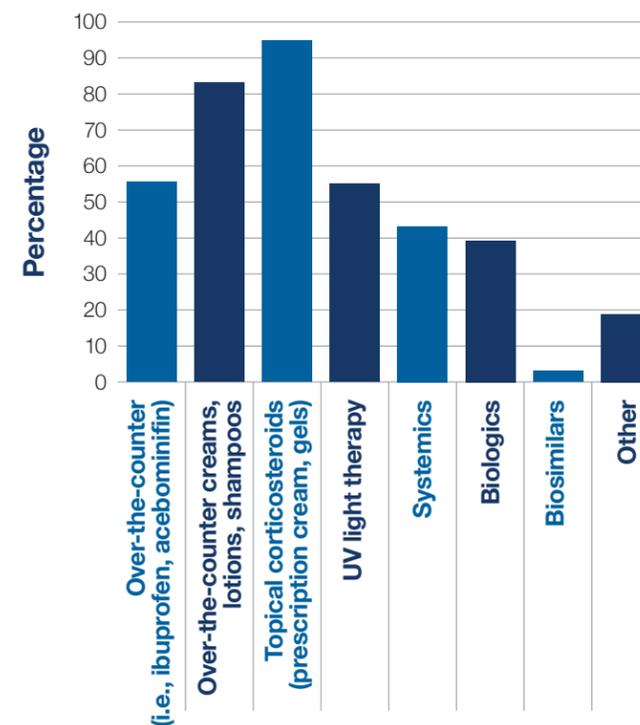
Attributes ranked in order of importance (where one is most important and 11 is least important).

1)	Feeling healthy
2)	Feeling confident
3)	Sleeping well
4)	Wearing certain types of clothes
5)	Satisfying social life
6)	Having a relationship
7)	Being intimate
8)	Being productive in career/job
9)	Going to the beach
10)	Exercising alone
11)	Exercising with others/joining a group

Table 1: Desired Attributes in Order of Importance

Since being diagnosed, individuals have tried many different medications. Not surprisingly, 94.22% have tried topical corticosteroids and over the counter creams, lotions, shampoos, and nail products (82.66%). Over 55% of respondents have tried UV light therapy, approximately 40% have tried biologics (39.91%) and 3.47% have tried biosimilars. Comments provided in "other" included specific alternatives such as: dead sea salts, acupuncture, antihistamines, diet, home remedies. Respondents did not indicate if the alternatives were used in addition to treatments prescribed, recommended by a physician or a replacement of treatments recommended by a physician.

Figure 15: Medications Tried Since Diagnosis



For those who feel their condition is controlled, there were a few themes that emerged.

People being able to:

- Wear certain types of clothing (shorts, bathing suits, short sleeved shirts, black colours, sandals, etc.)
- Live a healthy, better quality of life (exercising, diet, etc.)
- Go out in public without worrying about people staring or avoiding them
- Have a "normal life"
- Have confidence in themselves again
- Sleep better
- Travel
- Not feel stressed
- Have a clear scalp (or improved)
- Be intimate

Respondents with moderate-to-severe psoriasis that is not well-controlled were asked if they have discussed a biologic or biosimilar with their physician. Less than 50% (43.35%) have had a discussion about biologics with their physician.

Comments provided about why they have not had a discussion included:

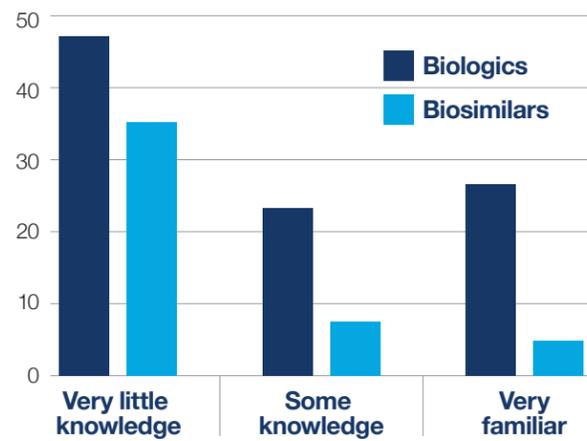
- I am stable/controlled on my current treatment
- Doctor has not recommended/considered it
- Didn't know about biologics
- Doctor not well-versed in psoriasis
- I've seen commercials on TV and know of the side effects and will not use these products

Comments provided about having had a discussion but not choosing a biologic include:

- Doctor not concerned
- Had breast cancer
- Biologics cause reduced immune system which leads to infections
- Fear of side effects
- Waiting for approval from insurance company to start/waiting to start treatment
- Past medical history with autoimmune disorders

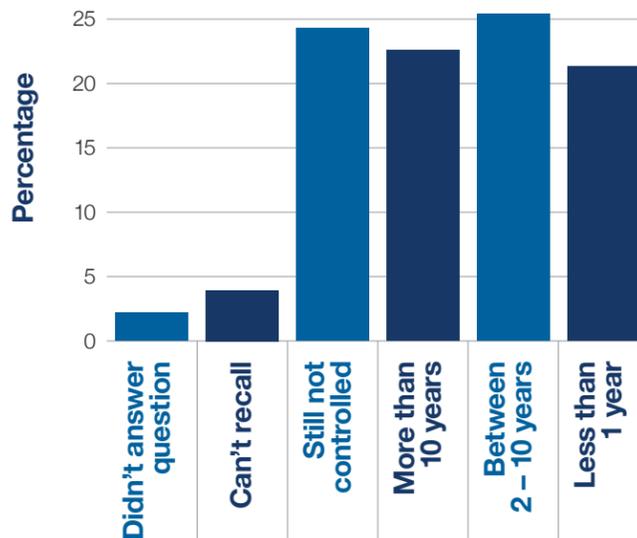
When asked about biologics or biosimilars, over 47% of people said that they had very little knowledge and 23% said that they had some knowledge. For biosimilars, 35% had very little knowledge and seven percent had some knowledge.

Figure 16: Knowledge of Biologics & Biosimilars



When respondents were asked how long after being diagnosed did it take until they considered their condition to be stable or well-controlled, it was fairly balanced. Of the 173 respondents who answered this question, over 24% are still not controlled.

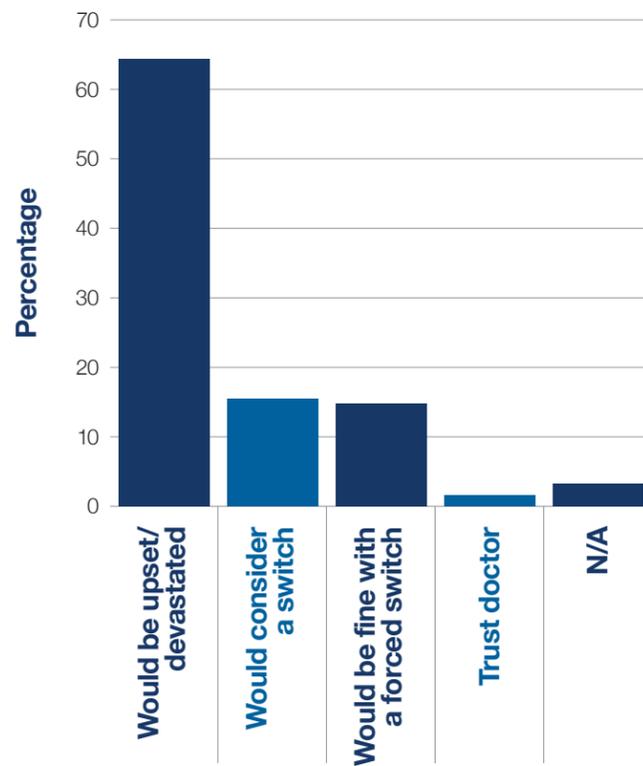
Figure 17: Length of Time to Controlled/Stable



When asked how respondents would feel if they were told they had to switch medications for non-medicinal purposes, while being stable/well controlled to another medication by someone other than his/her physician (i.e., lower-cost alternative, not covered by private insurance, not covered by public health plans), the majority, (64.16%) of people would find this very upsetting and would be extremely angry. Individuals who would be okay with, or who would consider, a switch were each 15%. Those who specifically indicated they would consider a change included comments around efficacy and more in-depth conversation with physician.

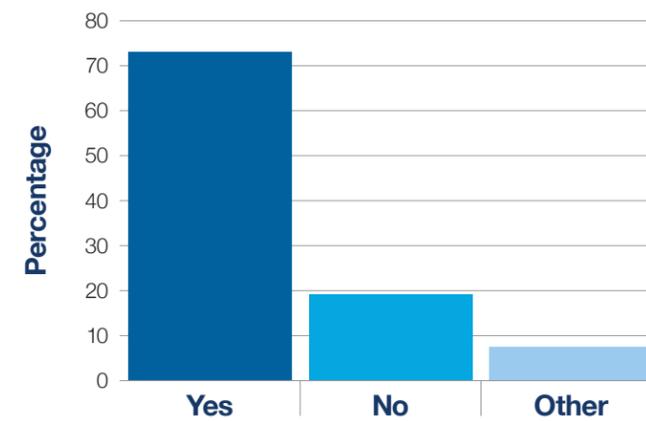
A few (1.7%) said they only trust their dermatologist to change their medication or that any change should be at the discretion of their dermatologist.

Figure 18: Response to Forced Switch



When asked if respondents feel involved in the decision about which medication they are prescribed, 73.4% feel they are a part of the decision and 19.08% do not feel they are involved with what is prescribed.

Figure 19: Involvement in Prescribed Medication



If forced to change medications, the majority of people (86.71%) would speak to their physician. A large number would write to the Minister of Health in their province, write to local government official or arrange a meeting with a decision maker/influencer. Only a handful (14 people or 8.09%) would bring the issue to their employer.

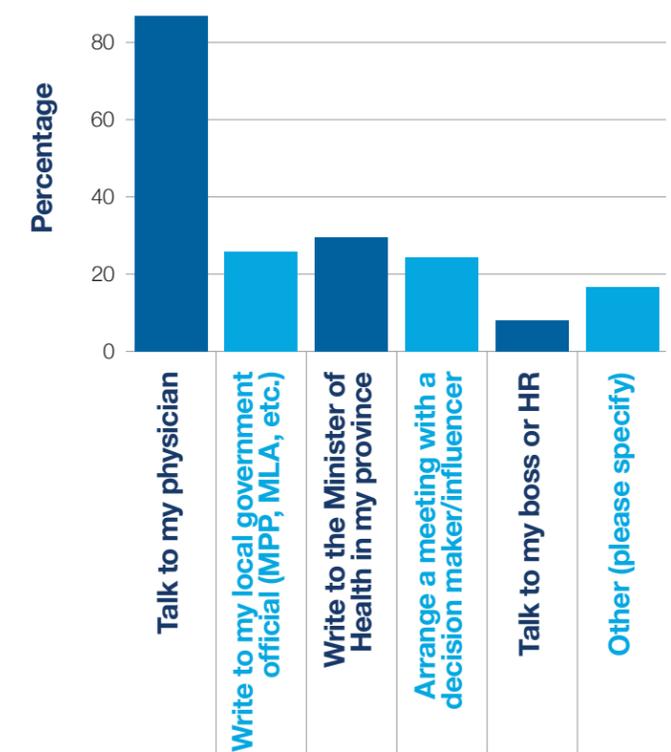
Individuals who provided comments varied from doing whatever it takes to stay on their medication including paying for it themselves, going to the news or social media outlets, looking for alternatives

“I pray to god to give me cancer and **take this psoriasis away**”

(going on another study) or not taking medication.

Figure 20: Action to Forced Switch

Reflecting back on when respondents changed medications because they weren't effective, the majority (65.32%) were negatively impacted.

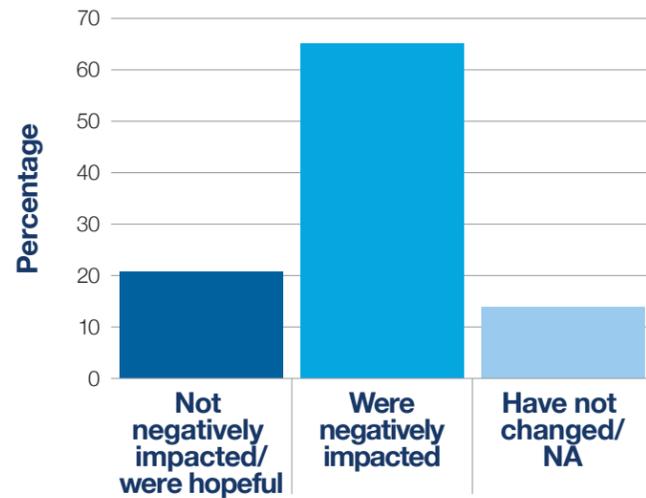


“Stable and controlled are interesting words and subject to individual interpretation. I do not believe my condition, or rather its symptoms, were ever controlled or stable.”

Approximately 20.81% indicated that they were not negatively impacted and were actually encouraged or hopeful by a change in medication and 13.87% have not changed medication yet.

Figure 21: Change in Medication Experience

When asked if respondents were comfortable discussing any dissatisfaction with response to medication or side effects being experienced with their physician, over



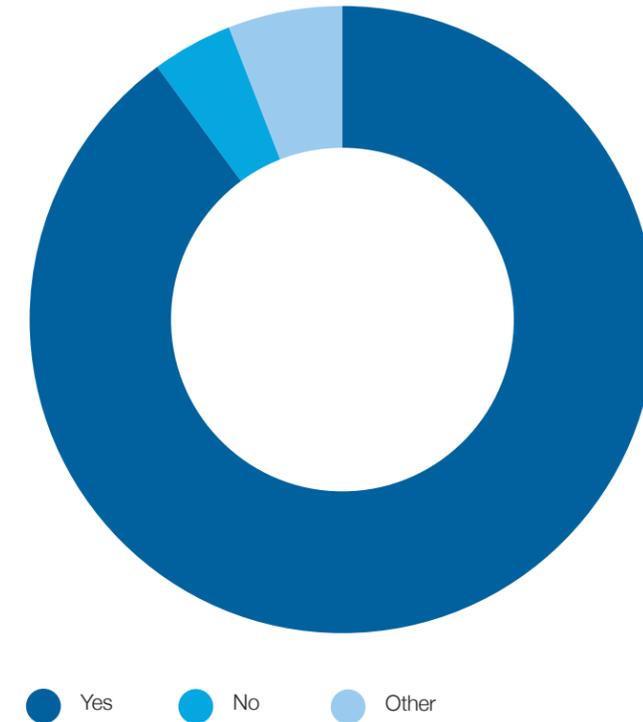
ninety percent (90.17%) were comfortable compared to 4.05% who were not comfortable.

Some repeated comments provided included:

- Yes, I can speak with my dermatologist candidly. She respects my opinion and I respect her knowledge and opinion. She is fabulous and I'm lucky to have her.
- Sometimes. It is not a yes or no. I have had my difficulties.
- I'm somewhat comfortable but I feel that my doctor doesn't really hear what I'm saying.
- Always told there's nothing more that can be done.

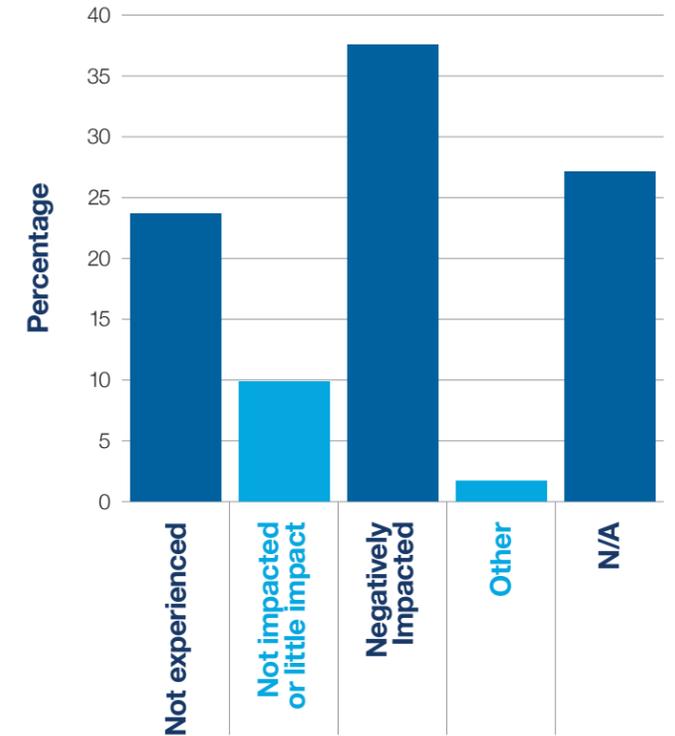
Figure 23: Impact on Wash-out Period/Time off Medication

Figure 22: Comfort with Discussing Dissatisfaction or Side Effects with Physician



When asked to reflect on a time when respondents had to take a break from medications because of an impending change in medication (commonly known as a wash-out period), the majority of respondents (37.6%) who answered the questions were negatively impacted either emotionally, physically, or both. Some (9.8%) were not really impacted and 23.7% have not experienced Effect of Wash-Out Period/Time Off Medication. There were 27% who responded “not applicable”.

Figure 23: Effect of Wash-Out Period/Time Off Medication



Examples of comments from those who were negatively impacted include:

- Once during a wash-out, I actually asked God if I could trade psoriasis for cancer. I felt like I just couldn't do this anymore. I felt if I could trade psoriasis for cancer I would at least stand a chance at a cure or an end
- It was tough
- Painful and depressing
- Absolutely horrible
- It was absolutely traumatizing... no words could describe that period accurately
- I lost my confidence and wouldn't go out only to work where I could wear a head scarf
- Time couldn't go fast enough

OBSERVATIONS & RECOMMENDATIONS

It became quickly apparent that psoriasis is a very subjective disease with the review and analysis of the results and comments in this survey. The results from the respondents who completed the survey in French were similar to those responding in English. The impact on people's quality of life and outlook is very different and unique. For many, psoriasis is a troubling disease that negatively affects their quality of life. For some, there is hope for new treatments and optimism that one day their condition will be manageable and they will feel healthy.

The majority of people who participated in the survey considered themselves to be in the moderate-severe range and that their condition is not well-controlled. Many have lived with their psoriasis for many years and still report that their disease is not well-controlled. An observation is that consideration should be given to how people can gain access to effective medicines more quickly. Resources and programs to empower people to not give up and to have open and honest dialogues with their physician about what is reasonable or acceptable to their life style, individual needs and abilities should be developed or made available.

When thinking about why individuals remain under treated and uncontrolled/not well managed, consideration should also be given to the complicated nature of treating psoriasis including time, energy and the financial burden. Lack of or limited education and resources on the different types of treatment options available in Canada is also a factor.

Comprehensive information and resources could help people be familiar with and assess options that could positively improve their outcomes and lead to informed discussions with their physician. Most people diagnosed with psoriasis are familiar with over-the-counter or prescribed creams and lotions, however, a significant number of people are not aware of newer treatment options (biologics and biosimilars). Some are concerned about the side effects and should be encouraged to discuss these with their physician, including the likelihood of encountering them and weighing the pros-and-cons in consideration of individual medical history.

Feedback from this survey concludes that overall, respondents were very concerned about the idea of being forced to switch medications for non-medical reasons when their condition is well controlled.

For the majority of people, this would cause significant distress and anxiety. A recommendation to decision-makers (private and public) is to consider patient choice and leave the decision for what treatment option makes best sense for each patient to the patient in consultation with their physician. Having access to real-world evidence (data) on patients who have switched would be helpful to both physicians and patients when discussing when or if to switch medications.

Recommendations summarized:

- 1) Reduce the length of time for accessing medications to lessen the time to people achieving control of their symptoms and being less impacted by their psoriasis. There continues to be a significant percentage of people who live with their condition unstable for several years.
- 2) Expand outreach to further educate physicians, patients and their loved ones/caregivers on psoriasis and its burden.
- 3) Continue to develop resources to educate individuals on treatment options available, including biologics and biosimilars. There continues to be too many Canadians with psoriasis not aware that these medications are options available to them.
- 4) Ensure the choice of therapy remains between the physician and the patient and be based on what is best for each patient with consideration given to his/her medical history and personal situation.

Although there is currently no cure for psoriasis, there are medications available to Canadians approved to treat the different severity stages of the disease and more are being developed that will provide options in the future. It is important to encourage and provide hope to psoriasis patients.

We hope that this report will provide the groundwork for education, awareness campaigns and programs in addition to further research in this area. It also provides a foundation for future assessment of progress towards the goal of optimizing the care of Canadians living with psoriasis.

“Biologics have completely changed my life. I am just like everyone else now. I can live my life to the fullest!”



**APPENDIX A:
FRENCH FEEDBACK SUMMARY**

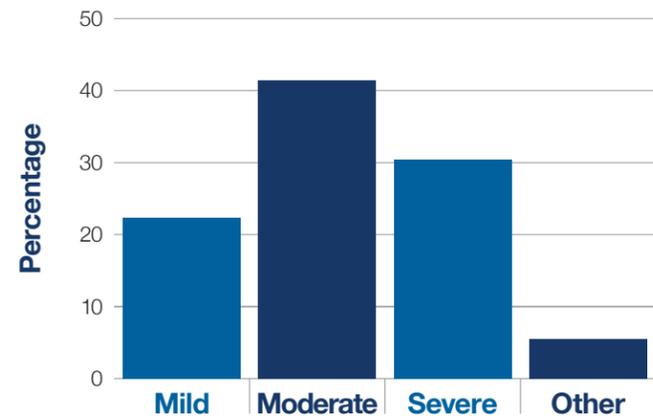
In total, surveys were completed by 36 French respondents with the majority (96.5%) being adults living with psoriasis. All respondents lived in the province of Quebec.

SECTION 1: WHO ARE YOU?

To better understand more about the individuals who participated, the first few questions were asked to provide general knowledge.

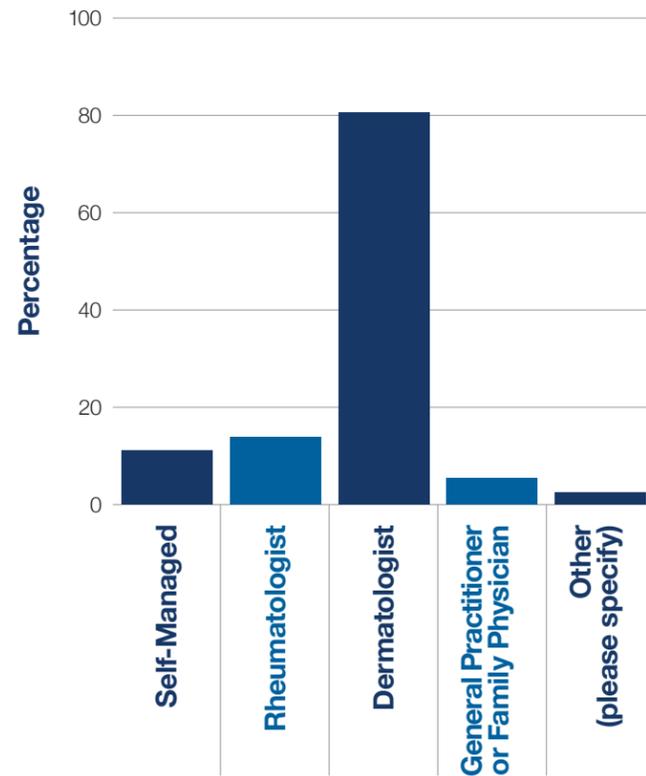
Respondents were asked to tell us what best describes their psoriasis (mild, moderate or severe); 41.67% described themselves as having moderate psoriasis, 30.56% described themselves having severe psoriasis and 22.22% described their condition as mild. The breakdown was very similar to the English responses. There were two individuals who selected the “other” category who were unsure of how to rate themselves as they were either severe or moderate in the past and are now improved, or drift between stages.

Figure 1: Description of Psoriasis



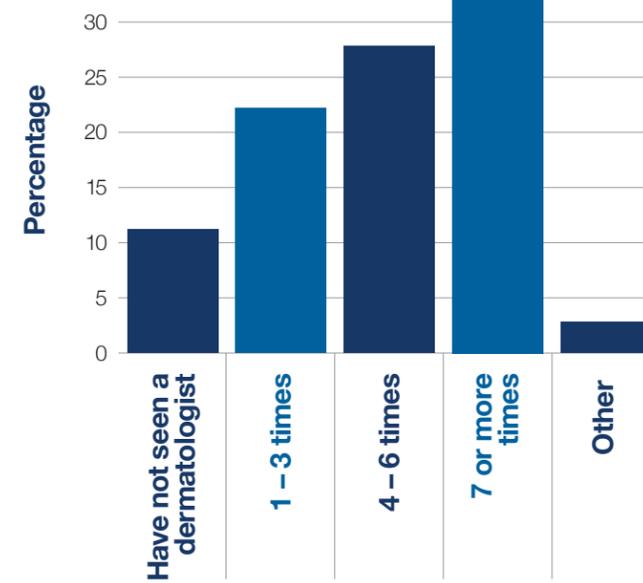
Respondents were asked to select all that apply with regard to who manages their treatment. The majority of respondents are seen by a dermatologist (80.56%), followed by 13.9% who see a rheumatologist. Only 5.56% see their family physician to manage their condition and 11.1% self-manage their condition.

Figure 2: How Treatment is Managed



When asked how many times over the past five years respondents have seen their dermatologist, 33.33% have seen their dermatologist seven or more times, followed by 27.8% who have been seen 4-6 times. Only 11% have yet to see a dermatologist. There were no reasons provided for those having not seen a dermatologist yet.

Figure 3: How Many Times a Dermatologist was Seen Over the Last 5 Years



For 38.9% of respondents, wait times to see dermatologists in Quebec were on average 1-3 months. Twenty-five percent of respondents waited 4-6 months and only 8% eight percent took between waited 7-18 months. A couple of respondents stated that it took years for an appointment.

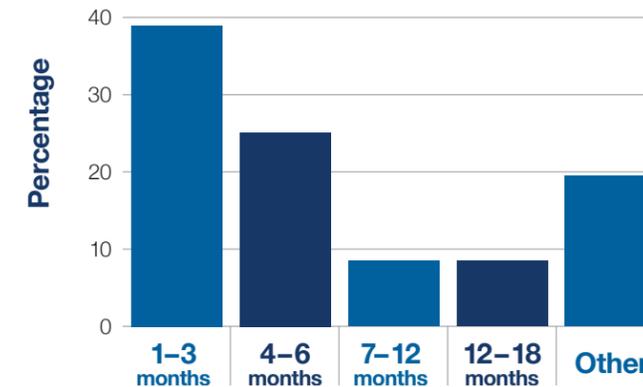
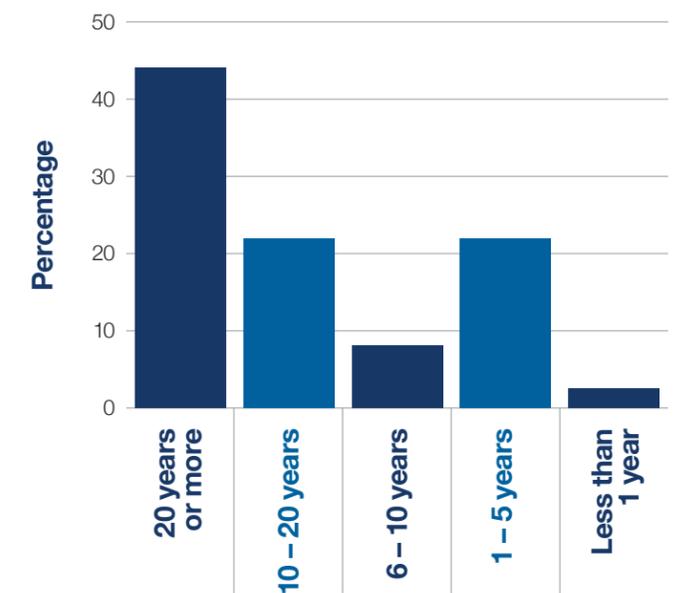


Figure 4: Wait Times to See a Dermatologist (%)

The length of time respondents who participated have been living with psoriasis for 10 years or more was 44.4%, followed by 22.2% between 10 and 20 years. There were 22.2% who have been living with psoriasis between 1-5 years.



“The worst thing is feeling really bad and embarrassed about how I look.”

Figure 5: Length of Time Individuals Have Lived with Psoriasis

SECTION 2: QUALITY OF LIFE

The emotional impact of psoriasis on a person’s life does not depend on the severity of the lesions. It is determined by how each person feels about the itchiness, pain and discomfort of psoriasis and the visibility of the lesions.

When asked if psoriasis negatively impacts respondents’ lives, 68% indicated that it had a negative impact on their quality of life. There was one person who responded that it did not affect their life and one who selected other. The majority of comments provided support that individuals are mentally impacted.

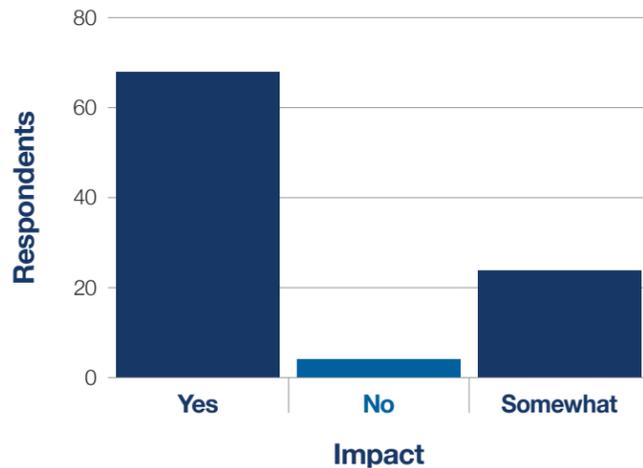


Figure 6: Impact on Quality of Life

Respondents were asked to select all the personal attributes experienced over the past few years; 61% of respondents selected anxiety, followed by 52% who felt psoriasis contributed to a lack of self-esteem and 44% experienced interrupted or loss of sleep.

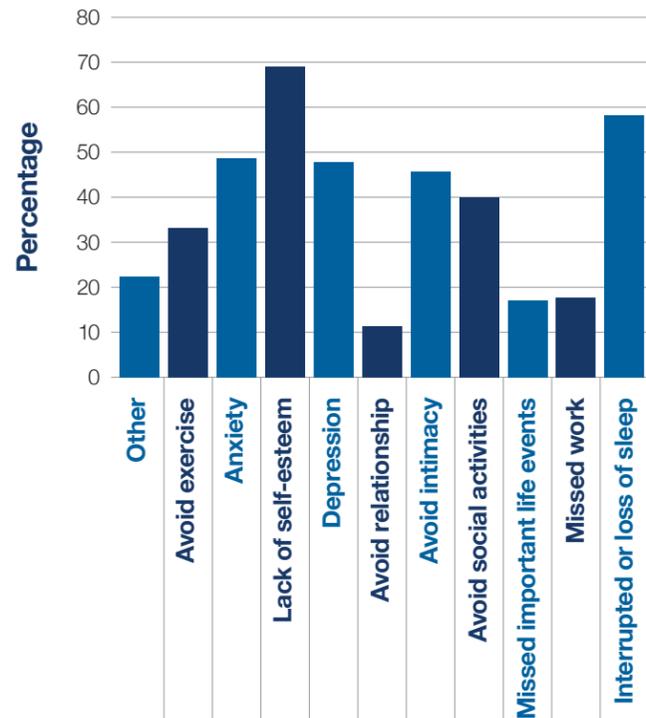


Figure 7: Attributes Negatively Affected by Psoriasis

Exploring further, when asked to rank the same attributes in order of importance, anxiety, self-esteem and lack of sleep remained the most important. When asked why sleep was interrupted, itchiness and pain were dominant (72% and 48% respectively).

Figure 8: Lack of Sleep Attributes

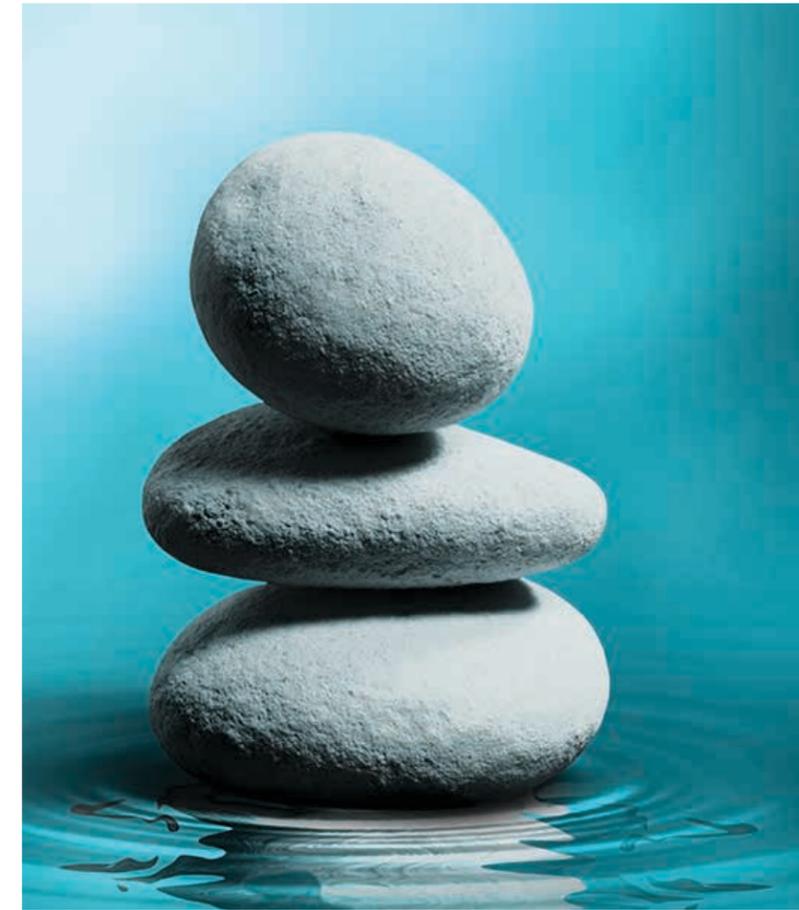
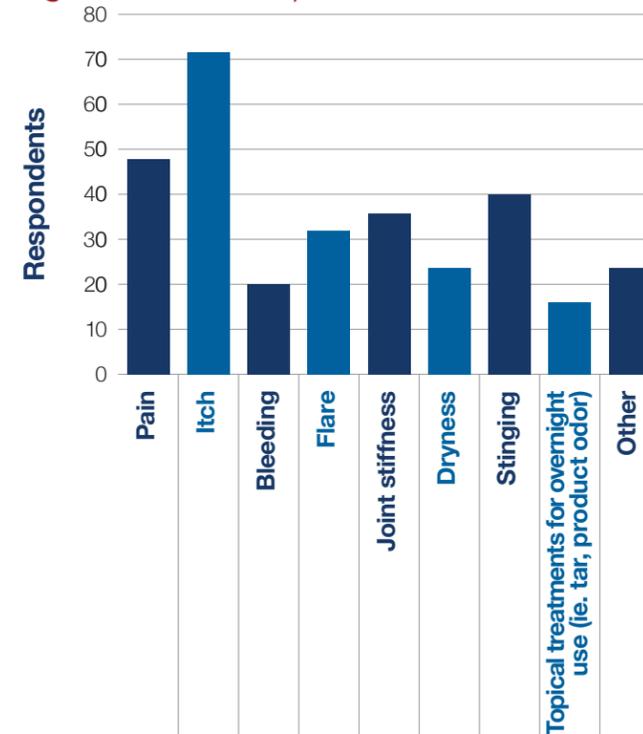
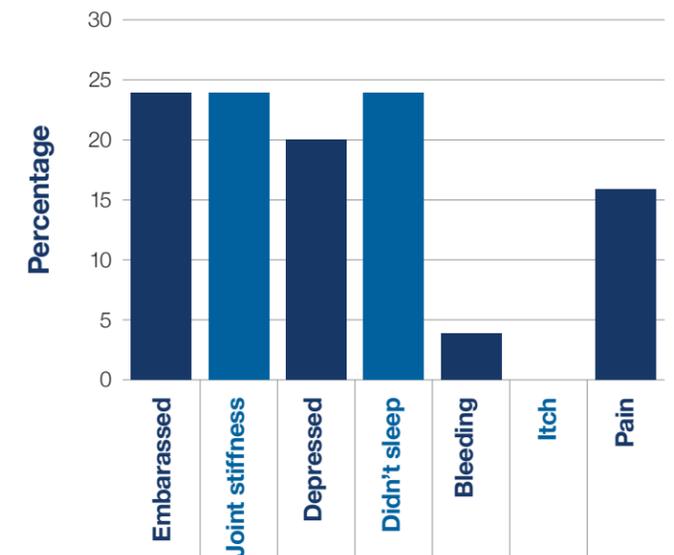


Figure 9: Reasons for Missed Work Days

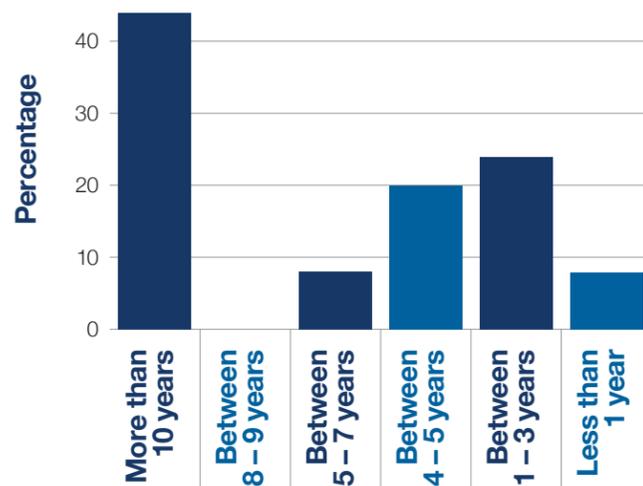
For individuals not able to work due to their psoriasis, respondents were asked to select all that apply. The reasons were fairly well balanced with lack of sleep, stiffness and embarrassed being equal, followed by depression. The majority of respondents have not missed work. There were 28% who have missed only 1-5 days of work and many commented it was for doctors’ appointments.



SECTION 3: JOURNEY TO STABILITY/ CONTROLLED PSORIASIS

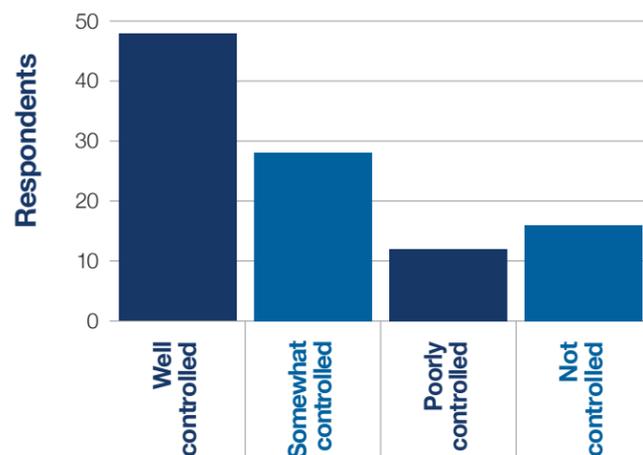
When asked how long they felt their condition to be unstable or uncontrolled, 44% indicated that they felt their condition was not satisfactorily controlled for 10 or more years. There were 20% of people who have lived with their condition uncontrolled for 4-5 years and 24% for 1-3 years.

Figure 10: Individuals Living with Uncontrolled/ Unstable Disease



When asked how well their psoriasis was under control, 48% of respondents felt their condition is well controlled and 28% felt it was “somewhat controlled”.

Figure 11: Individuals Living with Uncontrolled/ Unstable Disease



When asked to rank attributes in order of importance (where one is most important and 11 is least important) respondents chose:

Table 1: Attributes in Order of Importance

1)	Wearing certain types of clothes
2)	Feeling healthy
3)	Feeling confident
4)	Going to the beach
5)	Being intimate
6)	Having a relationship
7)	Satisfying social life
8)	Sleeping well
9)	Being productive in career/job
10)	Exercising alone
11)	Exercising with others/joining a group

Since being diagnosed, individuals reported having tried different medications to treat their psoriasis. Most people have tried phototherapy and an equal number of people have tried systemics or biologics.

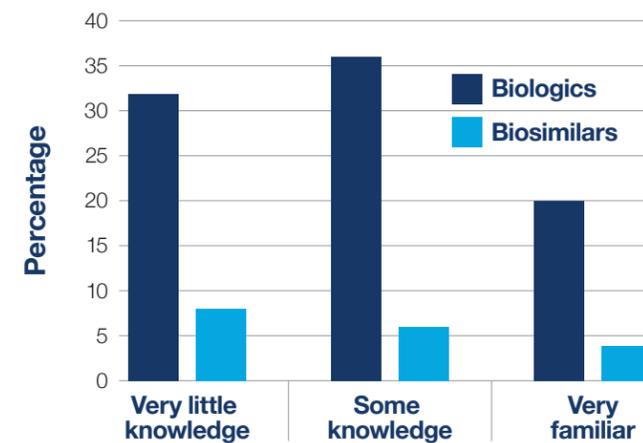
Respondents with moderate-to-severe psoriasis who are not well-controlled were asked if they have discussed a biologic or biosimilar with their physician. Less than half (43.35%) have had a discussion about biologics with their physician.

Comments provided about why they have not had a discussion included:

- I do not know what biologics or biosimilars are
- Cost too much

When asked about respondents’ knowledge of biologics or biosimilars, 36% think they have some knowledge and 32% of people said they had very little knowledge. There were two respondents who offered that they had very little knowledge of biosimilars and no respondents selected some or good familiarity of biosimilars.

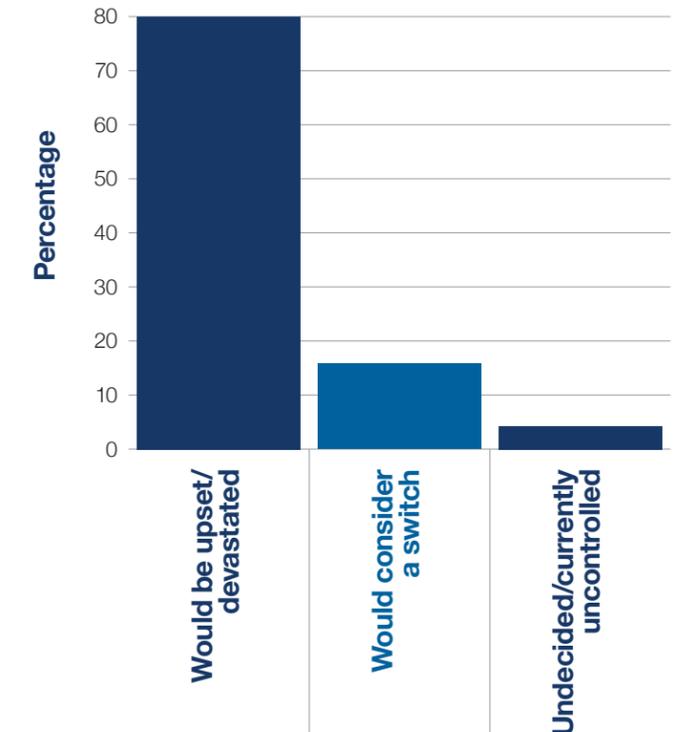
Figure 12: Knowledge of Biologics & Biosimilars



When asked how respondents would feel if they were told they had to switch medications for non-medicinal purposes, while being stable/well controlled to another medication by someone other than his/her physician (i.e., lower cost alternative, not covered by private insurance,

not covered by public health plans), the majority (80%) of people would find this very upsetting and would be extremely angry. Individuals who would be okay with or consider a switch were each 16%. Comments about efficacy and hopefulness were expressed by some of the few respondents who indicated that they would consider a change.

Figure 13: Response to Forced Switch



“Switching treatments is often what leads to flares and **worsening of symptoms.**”



When asked if respondents feel involved in the decision about which medication they are prescribed, 68% feel they are a part of the decision and 24% do not feel they are involved with what is prescribed. There were two people who chose other and didn't provide a reason for their choice.

Figure 14: Involvement in Prescribed Medication



If forced to change medicines, the majority of people (92%) would speak to their physician. Very few stated that they would write to the Minister of Health in

their province, write to local government official or arrange a meeting with a decision maker/influencer.

Comments provided include:

- Very disappointed and upset
- Really unhappy
- Very angry and in disagreement
Feeling of danger for myself and others
- It would disturb me, since I have a medication that works and they want to take it away
- It would be too bad to have to switch medication on a unilateral decision

When asked to reflect on a time when respondents had to take a break from medications because of an impending change in medication (wash-out period), the majority of respondents who provided feedback had not experienced a wash-out period. For the few, approximately 22%, experienced negative effects.

Reflecting back on when respondents changed medications because they were not effective, the majority commented that it was a difficult time. Some were open to change because their current treatment was not working and only two people said there was no impact.

When asked to reflect on a time when respondents had to take a break from medications because of an impending change in medication (wash-out period), the majority commented that they had not experienced this. A couple had heightened anxiety, psoriasis flare-up and joint pain.

“My mental health is **significantly improved** which impacts everything else.”





ACKNOWLEDGEMENTS

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