

Introduction

- There is a high prevalence of undiagnosed psoriatic arthritis (PsA) in psoriasis patients seen in dermatology clinics.
- The awareness of the prevalence of PsA, the consequences of delayed diagnosis and strategies for screening of psoriasis patients for PsA among Canadian dermatologists is unknown.
- The recently published Canadian Guidelines for Management of Plaque Psoriasis recommends that psoriasis patients be referred to a rheumatologist if they experience arthritis or arthralgia. However, since more than 50% of patients with psoriasis have rheumatic symptoms, this recommendation may lead to many inappropriate referrals.
- **We hypothesize that the awareness among patients with psoriasis and psoriatic arthritis (PsA) of disease outcomes and the available treatment options will influence dermatologists to refer patients who may have PsA to a rheumatologist.**

Aim

To explore the patients' disease knowledge and experiences in interacting with the health care system across Canada.

Methods

- An advisory group that is multidisciplinary in scope and includes dermatologists, rheumatologists and patients to define the priority actions/interventions/barriers that educational tools will need to target was established.
- Discussion topics for focus groups were developed based on recommendations from the advisory group.
- Patients with psoriasis only and those with psoriatic arthritis from across Canada were recruited via email and phone calls to participate in the focus group sessions.
- Focus groups were conducted in Vancouver, Winnipeg, Toronto, St. John's and 1 virtual focus group including participants from Quebec and Ontario.
- Six focus group with a total of 32 patient participants were conducted to elicit information on disease awareness, experience in the healthcare system, access to healthcare and suggestions to improve diagnosis and management.
- The focus groups were moderated by a research associate and research assistant. Each session was audio recorded, transcribed, and analyzed by 2 experts and then analyzed for key themes.

Results

- An **advisory group** consisting of four patients, two dermatologists and one rheumatologist was established to assist the research team consisting of two rheumatologists, 2 dermatologists, 2 methodologists and 2 research associates.

Results (2)

- The following question guides were utilized in the patient focus groups:
 1. To begin, can you tell me about your own **experience** with the healthcare system and having PsA/Psoriasis?
 2. When did you first think there might be a problem? [Probes: How and when were you diagnosed? Who gave you that **diagnosis**? How long were you living with pain or other symptoms before you were diagnosed?]
 3. Tell me what it is like to **live** with PsA/Psoriasis? [Probes: what effect does this have on your life? Your daily activities? Your relationships? Your sense of self?] How many years ago were you diagnosed with PsA?
 4. When you think back to when you were first diagnosed, do you think your PsA/Psoriasis was **identified early** enough? If your PsA/Psoriasis was not diagnosed early enough was it something you did that may have contributed to not getting that **early diagnosis**? (Probes: What do you think you could have done differently in your diagnosis of PsA/Psoriasis?)
 5. Can you tell me how your PsA/Psoriasis is **managed**? [Probes: do you take medications? Do exercises? See healthcare professionals regularly? If so, which professionals do you see and how often? Is your family doctor involved in your care for PsA/Psoriasis?]
 6. What do you think the **barriers** might be to getting PsA diagnosed early in patients with psoriasis? Probe: What could your doctors do differently?
 7. Is there anything that would have helped you or might help other patients with psoriasis get an early and proper **diagnosis** of PsA?
 8. Do you think that your condition is viewed as **complicated** or difficult to manage by your dermatologist or rheumatologist? (Probe: If so, why? If not, why not?)
 9. What do you **know about PsA** and other illnesses associated with psoriasis?
 10. Has your GP or dermatologist ever asked about **joint pain** or neck or back pain or stiffness? If so, when and how was it asked? Were you physically examined?]
 11. If you develop joint pain or prolonged neck or back pain what would be your next steps? [Probe- would you wait to bring this up with dermatologist or family doctor]
 12. Do you have any **suggestions for healthcare professionals** in caring for a person with PsA/Psoriasis?
- **6 focus groups** involving a total of **32 patient participants** with either dermatologist diagnosed psoriasis or rheumatologist confirmed PsA

Location	13	Ontario
	7	BC
	5	Newfoundland
	6	Manitoba
	1	Quebec
Gender	15 (47%)	Male
	17 (53%)	Female
Disease group	10 (63%)	PsC Female
	6 (38%)	PsC Male
	7 (44%)	PsA Female
	9 (56%)	PsA Male
Age	11 (34%)	>60
	10 (31%)	50-60
	6 (19%)	40-50
	4 (13%)	30-40
	1 (3%)	<30
Disease Duration	14.6 Years	PsA
	15.0 Years	PsC

Results (3)

The following themes were identified:

- (1) Finding a diagnosis:** Patients' recollections of their diagnostic journey were varied. Some patients indicated at least some difficulty with getting a definite diagnosis. Access to specialists and wait times were noted as problems to being diagnosed.
- (2) Knowledge about PsA:** There is a perception among the patients that PsA is a chronic condition marked by a lack of knowledge on both the patients' and healthcare professionals' part.
- (3) Benefits of early diagnosis:** Patients did not readily acknowledge the benefits of early diagnosis. Some questioned its benefit, wondering what would have been done differently in that case. Some participants also suggested that in their years of living with psoriasis and PsA, they see a change in how they are managed and this may assist with earlier diagnosis in the future.
- (4) Perceptions of the healthcare system/care received:** Patients perceive that their care is often fragmented and rushed. In their view, lacking a holistic approach to their psoriasis and its associated comorbidities. Patients with PsA also noted a lack of discussion with their dermatologists about arthritis, and the lack of co-ordination between specialities (dermatology and rheumatology). Patients also noted a lack of involvement of their primary care physicians in their psoriasis/PsA care. Most patients felt that nurses were helpful, knowledgeable, and approachable and understood the patient perspective better. Patients saw a role for electronic medical monitoring, but also education for both healthcare professionals and patients, particularly around the connection between psoriasis and PsA.
- (5) Disease management:** It was generally felt that management of their disease was difficult. Topical treatments for psoriasis were not very effective. There was also a general consensus that finding the right physician made a big difference. Access to specialists as well as to medications was also identified as problems.

Conclusions

- This qualitative study has identified themes that would have to be addressed to improve the care of patients with psoriasis and psoriatic arthritis in order to improve disease outcome and quality of life.

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