



# PSORIATIC ARTHRITIS: UNDERSTANDING THE PATIENT EXPERIENCE TO IMPROVE PATIENT SATISFACTION AND OUTCOMES

A summary of findings from a comprehensive social media analysis focused on patient perceptions of psoriatic arthritis.

## INTRODUCTION

Thank you for participating in “Psoriatic Arthritis: Understanding the Patient Experience to Improve Patient Satisfaction and Outcomes,” an interactive case-based CME activity.

While working to develop this activity, our educational partner, RealCME, conducted a comprehensive social media analysis using dialogue related to psoriatic arthritis (PsA) found on Facebook, Twitter, and Tumblr to compile a report titled “Social Media Blueprint: Patient & HCP Perspective on Psoriatic Arthritis.” This unique approach provided insight into the concerns and goals of patients with PsA, informing the faculty’s discussion of 3 cases—each of which focuses on practical strategies for shared decision making and a patient-centered approach.

RealCME analyzed 31,107 posts between 2015 and 2016 by 10,795 individuals in 16 countries (including Australia, Canada, Colombia, Germany, Spain, France, Honduras, Ireland, Italy, Mexico, Norway, New Zealand, the Philippines, Tunisia, United Kingdom, and the United States)—examining both the patient and the health care provider (HCP) perspective. Key themes emerged in the analysis of each group and were organized into several broad categories including “Diagnosis, Prognosis, and Treatment,” “Life-changing Nature of PsA,” “Importance of Support,” “Proactive Engagement,” and “Emotional Impact” for patients, and “Misinformation,” “Striking a Balance,” and “Treatment” for HCPs. This document summarizes the key issues identified in the analysis and addressed in the activity.

## PATIENTS

### Diagnosis, Prognosis, and Treatment

- The analysis revealed that many patients are frustrated with delays in diagnosis. Patients frequently discussed challenges encountered in receiving a timely and accurate diagnosis. Many patients, especially younger patients, often felt accused of lying about their symptoms. Conversely, older patients often dismissed their symptoms as a product of aging.
- Many patients described the diagnostic process as time-consuming and fraught with errors and missteps. Some patients said that it took over a decade to receive an accurate diagnosis.
- Both older and younger patients indicated some uncertainty about their future, and the impact the disease will have on their bodies. Many expressed a feeling of resignation that there is little they can do to change the course of the disease.
- Patients frequently expressed confusion about the therapies prescribed for them, especially if there were any inconsistencies in treatment or understanding compared to what other patients reported.

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- Overall, patients indicated a lack of consistent communication with their HCPs and often turned to the online community to help them understand treatment decisions, rather than making inquiries of their providers.
- Patients often expressed concern about possible comorbid diseases and/or side effects of treatment that make them more vulnerable to other diseases—cancers, in particular.
- Younger patients (aged <30) indicated that they were denied access to medication they needed and/or were treated with little regard to the severity of their symptoms. Some patients suggested that their HCPs seemed unsympathetic and/or unwilling to accept the impact the disease was having in terms of pain and mobility—younger patients felt that this bias was related to their age.

## Life-Changing Nature of PsA

- Patients often described the impact of PsA as life-changing. Formerly active, pain-free individuals wrote about their lives being taken over by crippling pain and disability. Many lamented “what might have been,” and expressed a sense of sorrow or loss often associated with PsA.
- Specific concerns included the cost of treatment, reduced employment, the risk for comorbid diseases, and the side effects of treatment that make them vulnerable to additional diseases.
- The impact of PsA on employment and insurance coverage was a common topic. For example, patients who identified as having severe PsA often indicated they are no longer able to work. Many reported concerns about the financial burden of PsA, as well as the strain on their relationships.



## Importance of Support

- Patients explained the importance of support and expressed gratitude to those who demonstrated understanding.
- Patients shared feelings of gratitude, acceptance, and relief especially for their fellow patients who provided emotional support and information from their own experiences.
- However, some patients indicated that they felt a lack of support from their HCPs. Some suggested that they were treated with skepticism, disbelief, or even derision when they discussed their symptoms before receiving a diagnosis. Of these patients, many indicated that they needed to change their HCP to achieve a correct diagnosis and start a treatment plan.



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## Proactive Engagement

- Some patients are extremely proactive, seeking advice and recommendations for managing their disease more effectively. This includes those who are newly diagnosed, as well as patients who have far more experience with the disease.
- Many patients use social media to explore options for managing their disease holistically or via alternative therapies, due to concerns about treatment side effects.
- Many patients also commented that they are struggling to find the right treatment strategy and are seeking advice about other treatments either because they have suffered side effects or because their current treatment has stopped working. It is not clear whether they are using social media to augment or replace conversations with their HCPs.
- Patients are also proactive about providing emotional support to each other, frequently expressing empathy and concern for those who have more severe disease and/or providing a sounding board for those who have not been able to get their PsA under control.

## Emotional Impact

- Patients often described the emotional impact of PsA. They are fearful of the long-term consequences of the disease, frustrated by the long process toward diagnosis, and concerned by the side effects associated with some treatments.
- Some patients expressed a sense of helplessness, and many seem resigned to a life of pain and disability, particularly if they have not responded favorably to treatment or have had to change treatments.
- Patients revealed frustration when they had to discontinue a treatment that impacts the immune system when they became ill or had surgery. They indicated that they felt stymied by the loss of progress they had achieved.
- Many patients cited the negative emotions as triggering flares and exacerbating their condition, and indicated they would like help managing stress. Some even spoke openly of suicidal ideation.
- Conversely, those who achieved positive treatment outcomes indicated that the treatment success gave them renewed vitality and enabled them to resume an active lifestyle.

## HEALTH CARE PROVIDERS

### Patient Misinformation

- HCPs express concern about the amount of information/misinformation that is available online, particularly from online communities that patients can access. Some encourage an abundance of caution, recommending that patients be proactive but judicious in the resources they access.
- Some HCPs report that their role is becoming more challenging as patients question or second guess prescribed therapy or insist upon treatments that may not benefit them, simply because they have read something online.

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## Striking a Balance

- HCPs recognize that PsA is a complex disease to manage, and that it is necessary to ensure that treatment is as streamlined as possible to ensure adherence. There needs to be a balance between patient goals and physician goals when developing individualized regimens that will promote adherence.
- While HCPs recognize the importance of improved quality of life as a goal for patients, some are concerned that patients do not always appreciate that effective treatment means managing disease progression and limiting the erosive effects of chronic inflammation on joint health and mobility. It is not always possible to achieve these goals in tandem.
- HCPs expressed concern regarding their ability to manage some of the more complex interactions with their patients, including navigating the psychological challenges faced by patients with chronic and/or painful conditions. This includes a lack of time available to fully engage with their patients.

## Treatment

- Some HCPs expressed concerns about effective treatments being too costly for patients.
- A few posts offered general advice about diet for patients with PsA.
- One HCP expressed extreme delight that a patient reported full remission of symptoms of PsA.
- One HCP discussed a new model of treatment designed to address gender inequalities.

## CONCLUSION

Patients are clearly working through a complex set of issues and actively seeking better information about what a diagnosis of PsA means for them. The faculty took this very seriously and emphasized that patient engagement, education, and collaboration must be carefully considered components of any therapeutic approach. Understanding patients' expectations, fears, and concerns will inform management strategies and build trust, and ultimately lead to better outcomes.

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