



BRIEF REPORT

Impact of Psoriatic Disease on Quality of Life: Interim Results of a Global Survey

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ABSTRACT

Introduction: Psoriatic disease (PsD) is a chronic systemic disorder affecting numerous body areas, including skin and joints. Patients' perspectives regarding understanding their disease and dialogue with healthcare professionals (HCPs) on treatment strategies is becoming

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increasingly important in the holistic management of PsD. The study aim was to determine patients' understanding of the systemic nature of psoriasis and psoriatic arthritis (PsA) and the associated burden of living with these diseases. The relationship between patient and HCP was also evaluated.

Methods: Psoriasis and Beyond: The Global Psoriatic Disease Survey was a cross-sectional, quantitative online survey, conducted in patients with moderate to severe plaque psoriasis with or without concomitant PsA. Here, we report interim analysis results.

Results: A total of 1678 respondents from 11 countries were included. Overall, 31% of patients with psoriasis reported concomitant PsA, 80% of whom considered their PsA severity as moderately or highly active. In total, 63% of patients had heard the term "psoriatic disease". Few patients were aware of psoriasis manifestations (PsA, 29%; axial symptoms, 18%) or comorbidities (obesity, 21%; cardiovascular disease, 18%). Among patients with psoriasis and concomitant PsA, 70% reported swollen and tender joints, especially of the finger(s) and/or toe(s). Most patients (84%) experienced stigma and discrimination and reported a negative impact of their disease on work, emotions, and relationships. Overall, 42% of patients had never discussed treatment goals with their HCP. Patients who were dissatisfied with their current treatment (psoriasis, 15%; psoriasis with PsA, 14%) reported incomplete

relief of skin symptoms (57%) and joint symptoms (45%) as primary reasons for dissatisfaction.

Conclusions: Despite many patients having heard the term “psoriatic disease”, the majority were unaware of the systemic nature and increased risk of comorbidities associated with PsD. This interim analysis highlights the need for patient education, productive patient–HCP dialogue, and shared decision-making in optimal disease management.

Keywords: Psoriatic disease; Psoriatic arthritis; Systemic inflammation; Psoriasis; Survey; Patients’ perspective

Key Summary Points

Why carry out this study?

Psoriatic disease is the overarching term used to describe the many manifestations of psoriasis, including psoriatic arthritis and the associated systemic comorbidities.

Psoriasis and Beyond: The Global Psoriatic Disease Survey was conducted among patients with moderate to severe plaque psoriasis with/without psoriatic arthritis to assess patients’ understanding of the systemic nature of psoriasis, psoriatic arthritis, and the associated burden of living with these systemic diseases.

What was learned from the study?

The interim results of this study demonstrated that despite many patients having heard the term “psoriatic disease”, the majority of patients were unaware of the systemic nature and increased risk of comorbidities associated with psoriatic disease. Further, psoriatic disease had a substantial negative impact on physical appearance, work, quality of life, emotions, and personal relationships.

On average, the confirmed diagnosis of psoriasis and psoriatic arthritis after first symptom was delayed by 2–3 and 2 years, respectively. Furthermore, many patients with psoriasis were found to be at risk of having psoriatic arthritis.

This interim analysis highlights the need for patient education, productive dialogue, and shared decision-making between patients and healthcare practitioners for optimal management of psoriatic disease.

INTRODUCTION

Psoriatic disease (PsD) is a systemic inflammatory disorder involving several manifestations of the skin, its appendages, and joints [1]. Despite advances in the treatment of psoriasis (PsO) and the various manifestations of PsD, medical unmet needs remain, including diagnostic delays and undertreatment [2–4].

There has been increased emphasis on understanding patients’ perspective, with a recent report indicating that patients feel empowered when they have a broader understanding of their disease and treatment options [5].

Psoriasis and Beyond: The Global Psoriatic Disease Survey was designed to assess patients’ understanding of the systemic nature of PsO and psoriatic arthritis (PsA), and the burden of living with these conditions. This survey also evaluated the relationship between patients and healthcare professionals (HCPs). Herein, we describe the interim survey results in patients with moderate to severe plaque PsO, and PsO with concomitant PsA (PsO-PsA).

METHODS

Survey Design

The survey is a joint research initiative among the International Federation of Psoriasis Associations (IFPA), dermatology experts, and

Novartis. This cross-sectional, quantitative online survey was conducted among patients (aged 18 years or more) from 20 countries across Asia, Australia, Europe, and North/South America with a self-reported diagnosis of moderate to severe plaque PsO or PsO-PsA. Criteria for participation included having a body surface area (BSA) of greater than 5 to less than 10 (moderate to severe) affecting sensitive and/or prominent body parts (face, palms, hands, fingers, genitals, soles of feet, or nails) or BSA of 10 or more (severe), when a patient's PsO was at its worst. Patients were recruited through online panels (agency or self-registered) by Institut de Publique Sondage d'Opinion Secteur (Ipsos SA) and patient advocacy groups (organized and coordinated by Novartis/IFPA). Primary data was collected following an eligibility assessment through a 5-min screener and subsequent 25-min online survey. The questionnaire consisted of a combination of validated tools such as the Dermatology Life Quality Index (DLQI), Work Productivity and Activity Index (WPAI), and the Psoriasis Epidemiology Screening Tool (PEST). All questions not included in the validated questionnaires were reviewed by the steering committee for appropriateness.

Objectives and Analysis

The primary objective of this survey was to assess patients' understanding of PsO/PsA as part of systemic diseases, and the humanistic and physical burdens of living with these conditions. Secondary objectives included assessing patients' attitudes to their relationships with HCPs, understanding the patient journey through the healthcare system, and assessing patients' perceptions on treatment expectations and satisfaction.

Analyses involved descriptive statistics and were performed by Ipsos SA.

Ethical Considerations

Informed digital consent was obtained from patients before survey participation. Where required, this study was reviewed and approved by local ethics committees/institutional review

boards, according to local laws and regulations. This study was performed in accordance with the Declaration of Helsinki of 1964 and its later amendments. No personally identifiable information was collected in this study.

RESULTS

Demographics and Disease Characteristics

Interim results involved 1678 responses (mean age 40.1 years; 52% women) from 11 countries (data collection November 2020–May 2021). At the time of the survey, 63% and 37% of patients reported having, at worst, moderate (BSA > 5 to < 10) and severe (BSA \geq 10) PsO, respectively. Overall, 31% of patients with PsO reported concomitant PsA; 80% of patients with PsO-PsA had moderately or highly active PsA. The most commonly diagnosed comorbidities were anxiety (31%), depression (27%), chronic gastrointestinal diseases (26%), and obesity (25%).

Patients' Disease Awareness

Overall, 63% had previously heard the term "psoriatic disease". Related to manifestations, only 29% of patients with PsO had heard about PsA and 18% about axial symptoms related to PsO (Fig. 1i). Few patients were aware of PsO-associated comorbidities (Fig. 1ii).

Physical Impact of Disease

At survey sampling, 57%, 26%, and 17% of patients reported currently having mild (BSA < 5), moderate, and severe PsO, respectively. Currently, patients described their scalp (57%), legs (56%), face (34%), genitals (19%), soles of feet (17%), palms (16%), and nails (15%) as the most affected body areas. In patients with PsO-PsA ($n = 517$), swollen and tender joints, especially in the finger(s) and/or toe(s), were the most commonly experienced symptoms (70%), followed by heel pain (46%), morning stiffness (45%), and swelling on the back of the leg, above the heel (45%).

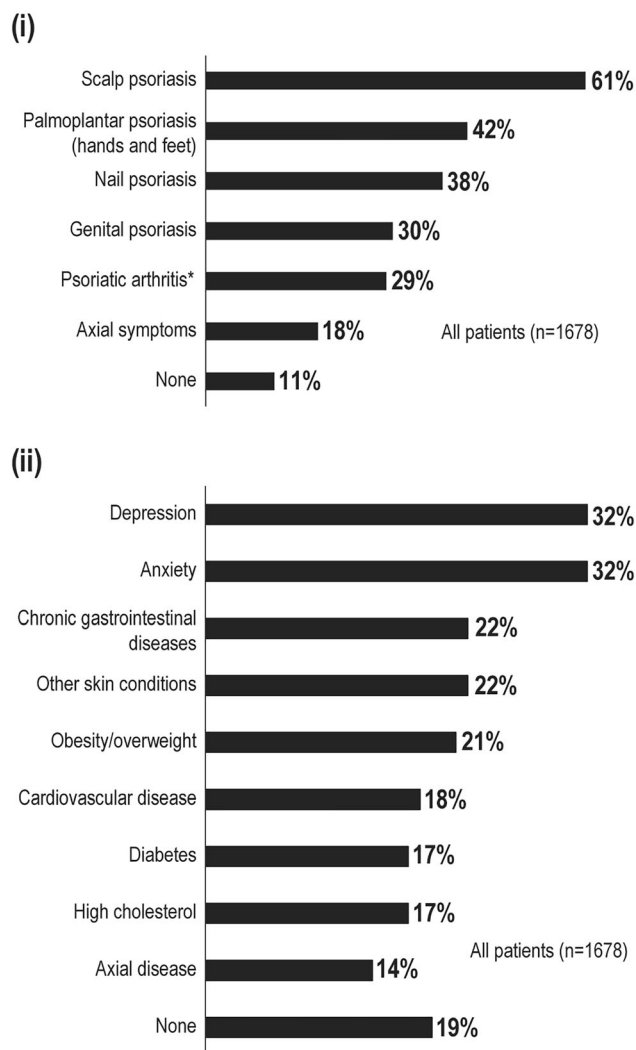


Fig. 1 Proportion of patients aware of the manifestations related to psoriatic disease (i) and associated comorbidities (ii). *Question addressed to patients with psoriasis only

PEST, a validated questionnaire used to identify early signs/symptoms of PsA [6], was employed in this survey. Among all patients with PsO without a PsA diagnosis completing the PEST questionnaire ($n = 1161$), 68% screened positive, indicative of a potential PsA presence. Among patients experiencing any joint symptoms during the previous year, 69% reported asking their HCP about them.

Disease Burden and Impact on Quality of Life

DLQI tool ranges [7] were used to evaluate the impact of PsO on quality of life (QoL). Over half of all patients (54%) reported a “very large” (DLQI scores 11–20) to “extremely large” (DLQI scores 21–30) impact on their QoL while only 28% indicated either “no impact” (DLQI score 0–1) or a “small impact” (DLQI scores 2–5).

One-third of all patients felt ashamed of their skin (35%) or body (30%) (Fig. S1 in the

supplementary material). Most patients experienced stigma and discrimination (84%) and an impact on their past or current relationships with their partners (82%) (Fig. S1).

Using the WPAI, on average, patients reported a moderate impact of their health on daily activities. Overall, 35% of all patients could not work/study the week prior to the survey as a result of their skin problems. Overall, 14% reported that their work/career choice was influenced by their disease. The main coping mechanisms for patients were talking with family and friends, engaging with social media and exercise/sport, and finding comfort in food.

Patients' Relationship with HCPs

Less than half (47%) of patients with PsO-PsA ($n = 517$) were being managed by rheumatologists (Fig. S2 in the supplementary material). Overall, 42% never discussed treatment goals with their HCPs, 44% decided together, and for 13% the HCP made this decision. HCPs and patients' treatment goals are provided in Fig. 2i and ii, respectively.

Understanding Patient Journey Through the Healthcare System

The mean time between symptom onset and confirmed medical diagnosis was 2.6 years for patients with PsO and 1.8 years for patients with PsO-PsA. Overall, 47% of patients with PsO were currently being treated with biologic therapy (Fig. 3i). For patients with PsO-PsA, 56% and 52% were receiving biologics and non-steroidal anti-inflammatory drugs, respectively (Fig. 3ii). Patients with PsO and PsO-PsA received 2–3 biologics since initiating treatment. Patients with PsO-PsA also received 2–3 disease-modifying antirheumatic drugs. Overall, 55% of patients with PsO could not recognize any change in their skin symptoms with their current treatment. Almost half of patients with PsO-PsA (46%) reported that their current treatment achieved an improvement in their condition.

The COVID-19 pandemic impacted current PsO and PsA treatment by 54% and 61%,

respectively. Almost one-third of patients with PsO and PsO-PsA reported treatment discontinuation and difficulty in getting prescriptions because of COVID-19 (Fig. 3iii).

Patients' treatment perceptions

Patients with PsO ($n = 1626$) and PsO-PsA ($n = 500$) reported similar degrees of dissatisfaction with current treatment (15% and 14%, respectively). Prime reasons for dissatisfaction (Fig. 3iv) were incomplete relief of skin (57%) and joint (45%) symptoms and no improvement in overall QoL (45%).

DISCUSSION

These interim global survey results revealed that, although many patients with moderate to severe PsO with or without concomitant PsA had previously heard the term “psoriatic disease”, they were predominantly unaware of the systemic nature of PsD and risk of associated comorbidities. On the basis of recent guidelines, HCPs recognize the need to address this systemic nature [8–11]. Increasing awareness of the systemic nature of PsO may improve a patient's understanding that there is more to PsO than skin symptoms [12]. Patients should be made aware of the relationship between the risk of PsO-associated comorbidities and lifestyle choices, such as alcohol and smoking [8, 9, 13, 14].

PsD had a negative impact on physical appearance, work, QoL, emotions, and relationships which may lead to psychological issues; patient counseling can help alleviate such issues [5]. The survey findings highlight that active involvement of the patient in setting treatment goals is required as both the patient and HCPs need to communicate openly about their objectives.

Facial PsO was reported by 34% of patients which was similar to results from a large Danish study (~ 30%) [15]. The same study termed scalp, face, nails, soles, genitals, and palms as hard-to-treat areas, even in patients with mild PsO, which remains a treatment challenge [15].

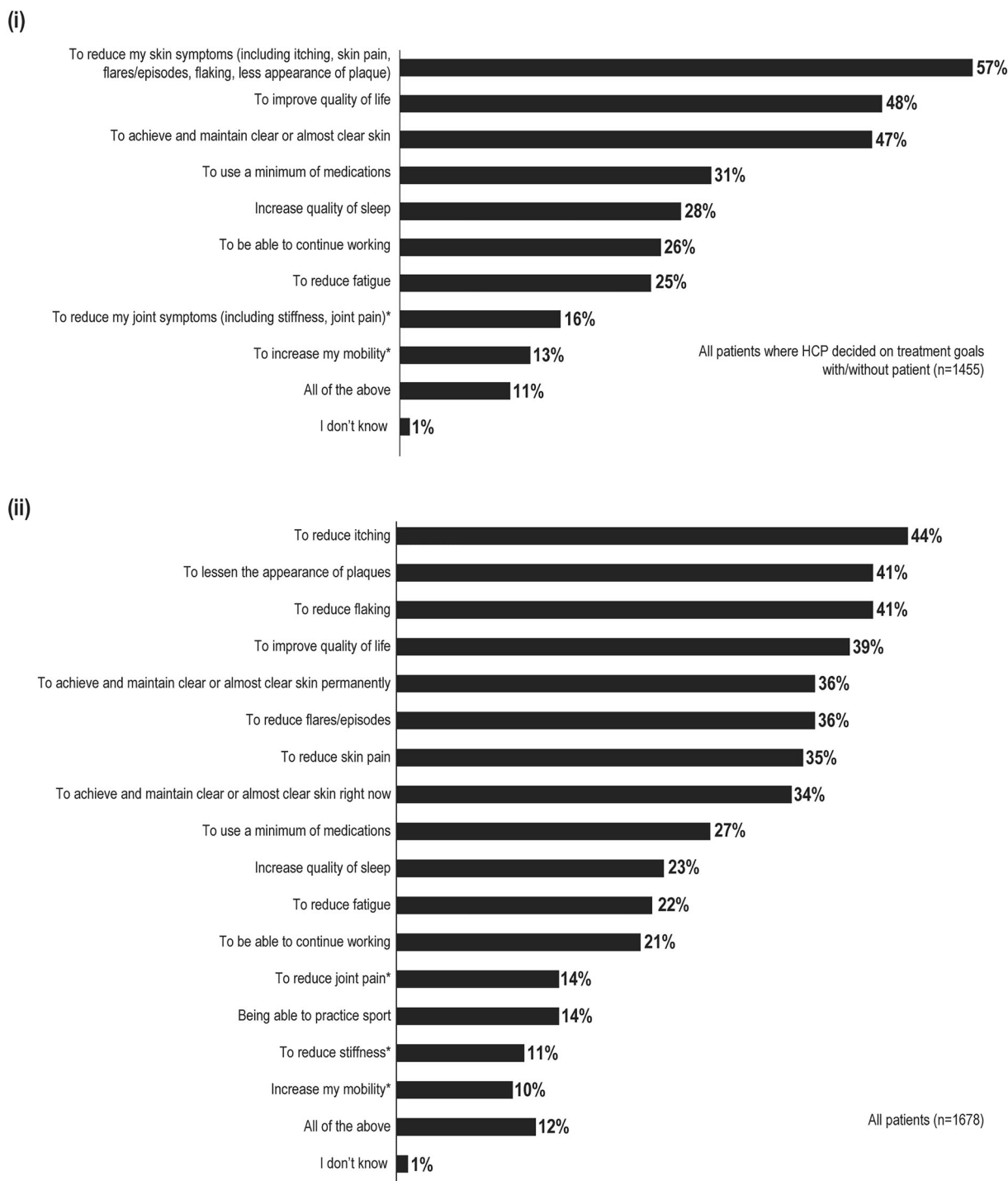


Fig. 2 Treatment goals aligned with HCP (i) and patients' personal treatment goals (ii). HCP, healthcare professional. *Question addressed to patients with psoriasis and psoriatic arthritis

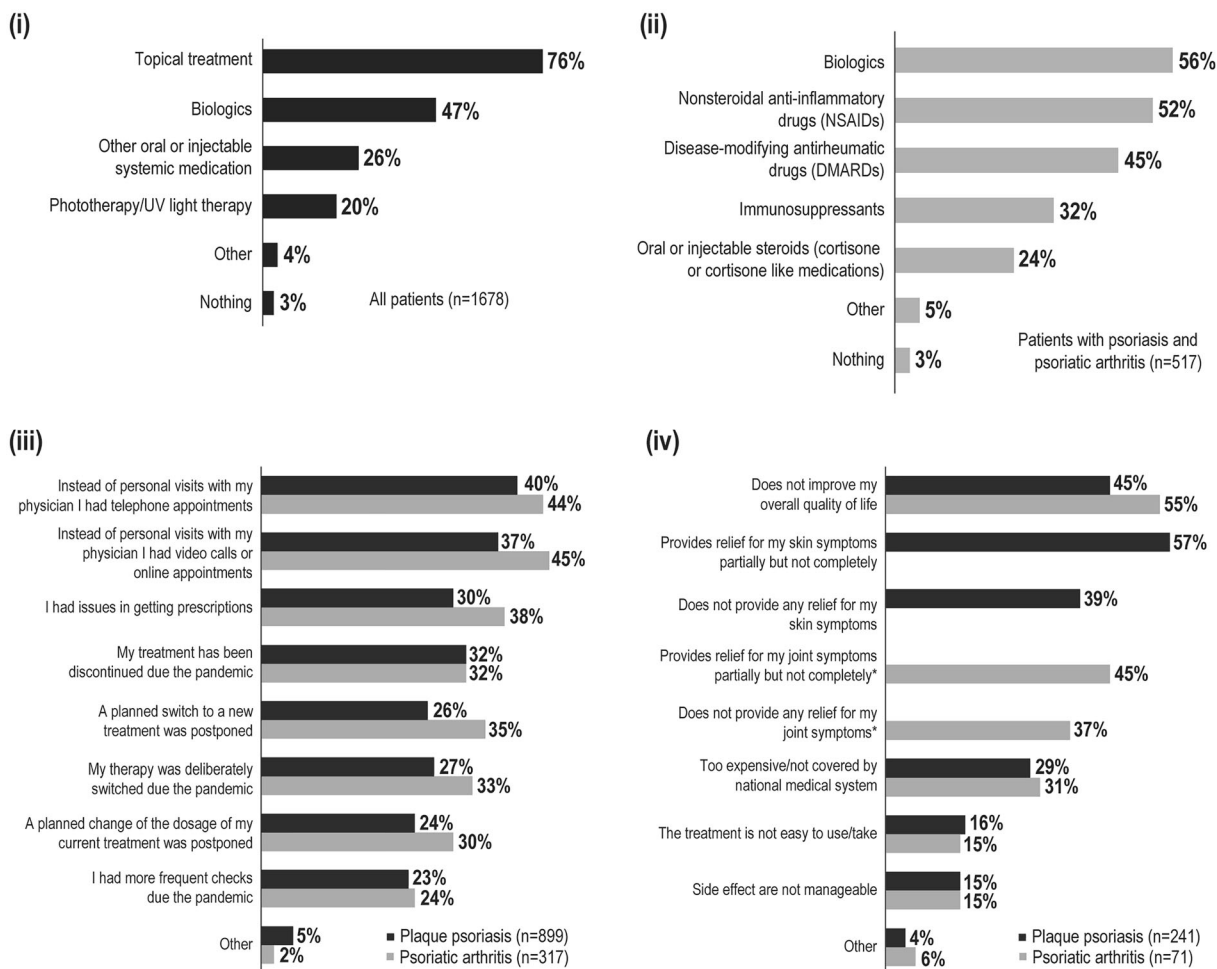


Fig. 3 Treatments currently received by patients with psoriasis (i) and psoriasis with psoriatic arthritis* (ii). Impact of the COVID-19 pandemic on treatment (iii) among patients with psoriasis or psoriatic arthritis and

reasons for treatment dissatisfaction provided by dissatisfied patients with psoriasis or psoriatic arthritis (iv). COVID-19, coronavirus 2019. *Question addressed to patients with psoriasis along with psoriatic arthritis

The study findings suggests that gaps exist in screening for PsA by dermatologists. Such screening can facilitate early diagnosis and treatment of PsA, preventing irreversible joint damage. Our results show that a considerable proportion of patients with PsO had previously undetected joint symptoms. Furthermore, early diagnosis of both PsO and PsA is pertinent in effective treatment and management of the disease [4], as a substantial delay was reported by patients between symptom onset and the confirmed diagnosis of PsO/PsA. Patient education with a focus on monitoring joints for early

detection of PsA may enable early access to treatments [16].

These results demonstrated that less than half of patients with PsA were treated by a rheumatologist. This may lead to disease mismanagement, with patients treated by non-specialists.

As this survey is based on patients' perspective, it is limited by inaccurate information recall, misinterpretation of questions, and varying understanding of the disease. The survey format did not consider differences in demographics, medical history, disease duration, type of visit (clinic or hospital) and

department being visited by the patient, and healthcare systems. Furthermore, the specific patient recruitment may have led to a selection bias and the study results may not be representative for the overall population of patients with psoriasis/PsA.

These interim findings underscore the need for increasing awareness of the systemic aspect of PsD and need for patient educational programs, since PsD impacts patients' physical and mental health. Evaluation of the impact of disease, treatment burden, productive patient–HCP dialogue, shared decision-making, and understanding of patients' perspectives is important so that improved strategies can be implemented to enhance overall QoL of patients.

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Compliance with Ethics Guidelines. Informed digital consent was obtained from patients before survey participation. Where required, this study was reviewed and approved by local ethics committees/institutional review boards, according to local laws and regulations. This study was performed in accordance with the Declaration of Helsinki of 1964 and its later amendments. No personally identifiable information was collected in this study.

Data Availability. The datasets generated and/or analyzed during the current study are not publicly available. Novartis is committed to sharing with qualified external researchers access to patient-level data and supporting clinical documents from eligible studies. These

requests are reviewed and approved on the basis of scientific merit. All data provided are anonymized to respect the privacy of patients who have participated in the trial in line with applicable laws and regulations. The data may be requested from the corresponding author of the manuscript.

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