A Closer Look at Patients' Perspectives on Psoriatic Disease Burden: Results from the Global Survey Psoriasis and Beyond

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Synopsis

- Recent clinical guidelines recognize psoriasis (PsO) as a multisystem inflammatory disorder with emphasis on comorbidity management.[1] The term 'psoriatic disease' (PsD) encompasses the multifaceted inflammatory nature of PsO that affects skin, its appendages and joints and can be complicated by systemic comorbidities[2]
- Patients' awareness of the systemic nature of PsD remains insufficiently explored. Psoriasis and Beyond: The Global Psoriatic Disease Survey is a joint research initiative between IFPA, medical experts, and Novartis

Objectives

- The study's primary objective was to assess patients' understanding of PsO and psoriatic arthritis (PsA) as part of systemic disease and the humanistic and physical burden of living with these conditions
- Secondary objectives included assessing patients' attitudes to their relationships with health care professionals (HCPs), their perceptions on treatment expectations and satisfaction, and understanding patient journey through the health care system

Methods

Study design and patients

- A cross-sectional, quantitative online survey conducted in patients (aged ≥18 years) with a self-reported diagnosis of moderate to severe (body surface area [BSA] >5% to <10%), affecting sensitive and/or prominent body parts (scalp, face, palms, hands, fingers, genitals, soles, or nails or BSA ≥10%) PsO at its worst, with/without concomitant PsA
- Patients were recruited through online panels (recruited by Institut de Publique Sondage d'Opinion Secteur; Ipsos SA) and patient advocacy groups (organized and coordinated by IFPA and Novartis)
- Eligible patients were recruited from 20 countries (Austria, Australia, Belgium, Chile, Canada, Denmark, France, Germany, India, Ireland, Italy, Japan, Norway, Romania, Russia, Slovenia, South Korea, Taiwan, UK, and USA)
- Primary data were collected following assessment of participant eligibility via a 5-minute screener followed by a 25-minute survey. Answers were based on patients' estimations and perceptions only
- The interim results analyzed 1678 responses from 11 countries and were presented at the 6th World Psoriasis and Psoriatic Arthritis Conference 2021. Further analyses are presented here

Statistical analysis

- As the study is descriptive, results for the primary and secondary objectives are reported descriptively

Results

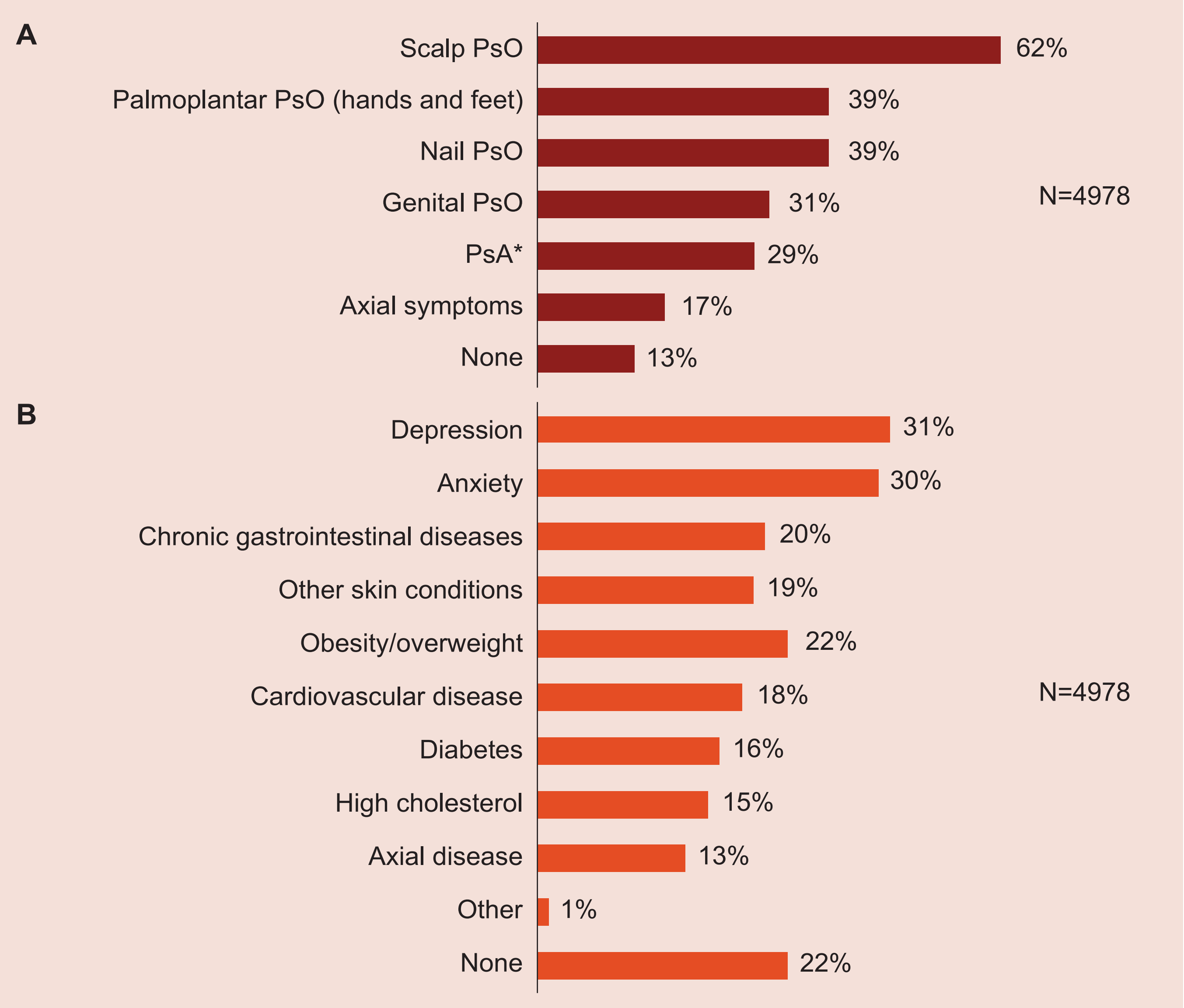
Baseline demographics and clinical characteristics

- A total of 4978 responses were analyzed, of which 51% were women (age, 44.0 years) and 49% were men (age, 42.5 years). A total of 4034 patients were recruited via online panels and 944 patients via patient advocacy groups
- Overall, 63% of patients had moderate and 37% had severe PsO at worst; 30% had concomitant PsA at the time of recruitment
- Furthermore, using the self-assessment Psoriasis Epidemiology Screening Tool (PEST) for PsA in PsO-only patients (n=3490), an additional 38% of patients screened positive for PsA
- Of the PsO-only patients receiving biologics, 55% screened positive for PsA using the PEST tool

Awareness of the psoriatic disease

- The results showed that 69% and 60% of all the patients (N=4978) surveyed had previously heard the terms 'systemic disease' and 'psoriatic disease', respectively
- Patients' awareness related to manifestations and comorbidities are presented in **Figure 1**

Figure 1. Awareness of manifestations of PsD (A) and comorbidities (B) that may be related to the disease

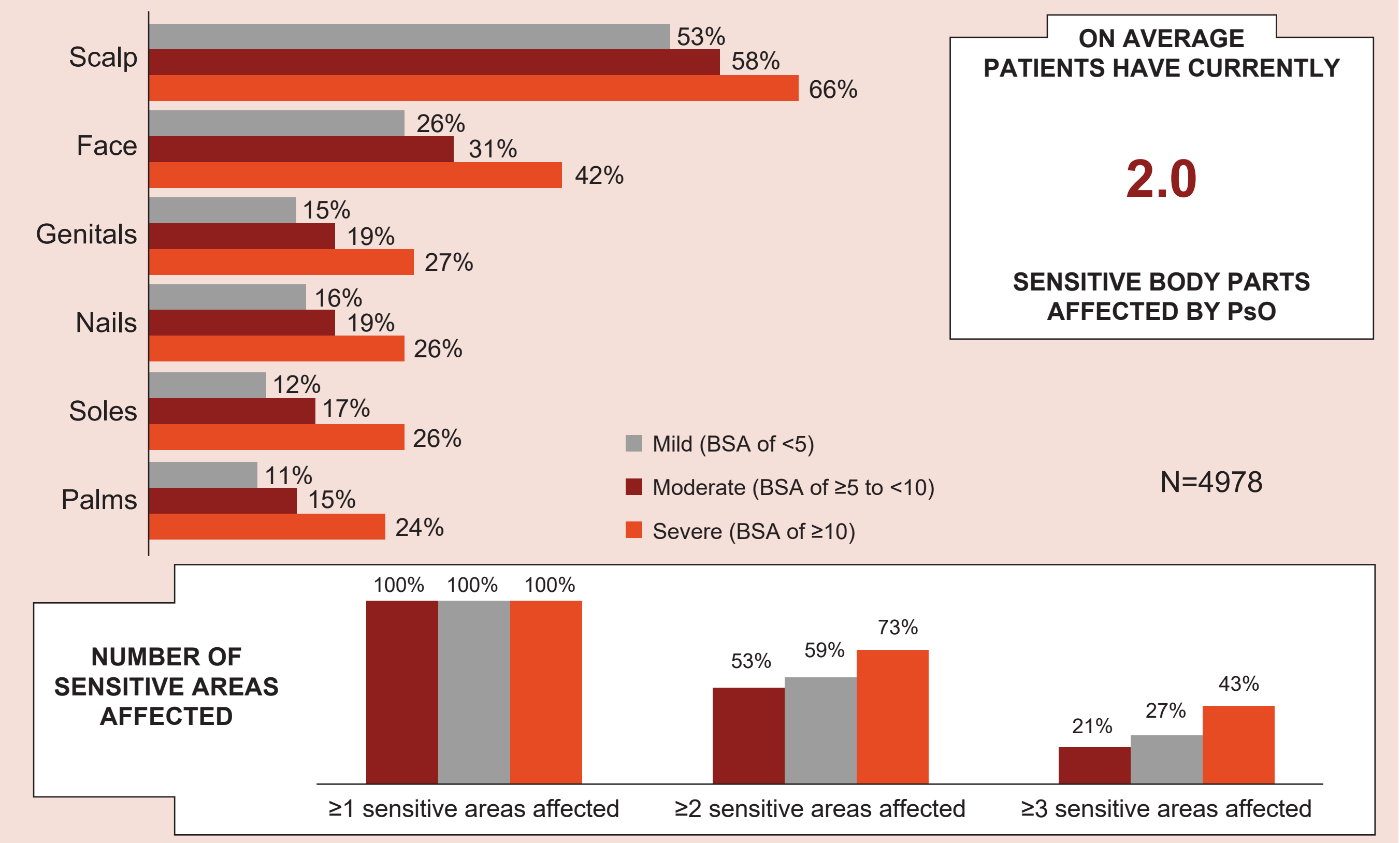


*Only shown to PsO-only patients.
PsA, psoriatic arthritis; PsD, psoriatic disease; PsO, psoriasis.

Physical impact of the psoriatic disease

- Findings showed that currently 60% of PsO patients suffered from a mild form, while 24% and 16% had moderate and severe PsO, respectively
- Patients described legs (57%) and scalp (56%) as the most affected areas of the body, followed by face (30%), genitals (18%), nails (18%), soles (15%), and palms (14%)
- Among PsO patients with PsA (n=1488), swollen and tender joints, especially in the finger(s) and/or toe(s) were the most commonly experienced symptoms (72%), followed by heel pain (43%) and morning stiffness (41%)
- On average, patients had 2 affected sensitive areas, despite 60% currently having mild PsO (**Figure 2**)

Figure 2. Affected sensitive areas by PsO severity



BSA, Body surface area; PsO, psoriasis.

Impact of the psoriatic disease on quality of life and emotional well-being

- Of all patients surveyed (N=4978), 69% of patients experienced a moderate (Dermatology Life Quality Index [DLQI] score: 6–10) to extremely large (DLQI: 21–30) impact on their quality of life (QoL). Among patients who reported extremely large effect on QoL, most (66%) had clear skin with the current treatment. In patients with very large to extremely large effect on QoL, anxiety (64%), depression (63%), and obesity (56%) were the commonly diagnosed comorbidities
- Overall (N=4978), 28% of patients could not work/study in the prior week due to skin problems. Patients screening positive for PEST (n=1340) were more impacted by their condition; 40% could not go to work due to their skin symptoms
- Among all patients (N=4978), majority (82%) experienced stigma and discrimination; mostly they had experienced being asked if they were contagious (35%), being stared at in public (32%), not benefitting from the understanding of other people regarding the impact of the disease on their life (32%)
- Living with PsO was associated with the following feelings: ashamed of their skin (35%) or body (30%), less self-confident (35%), depressed (28%) and unattractive (28%)
- Of 4978 patients, four-fifths (81%) reported the disease impacted past or current relationships with their partners

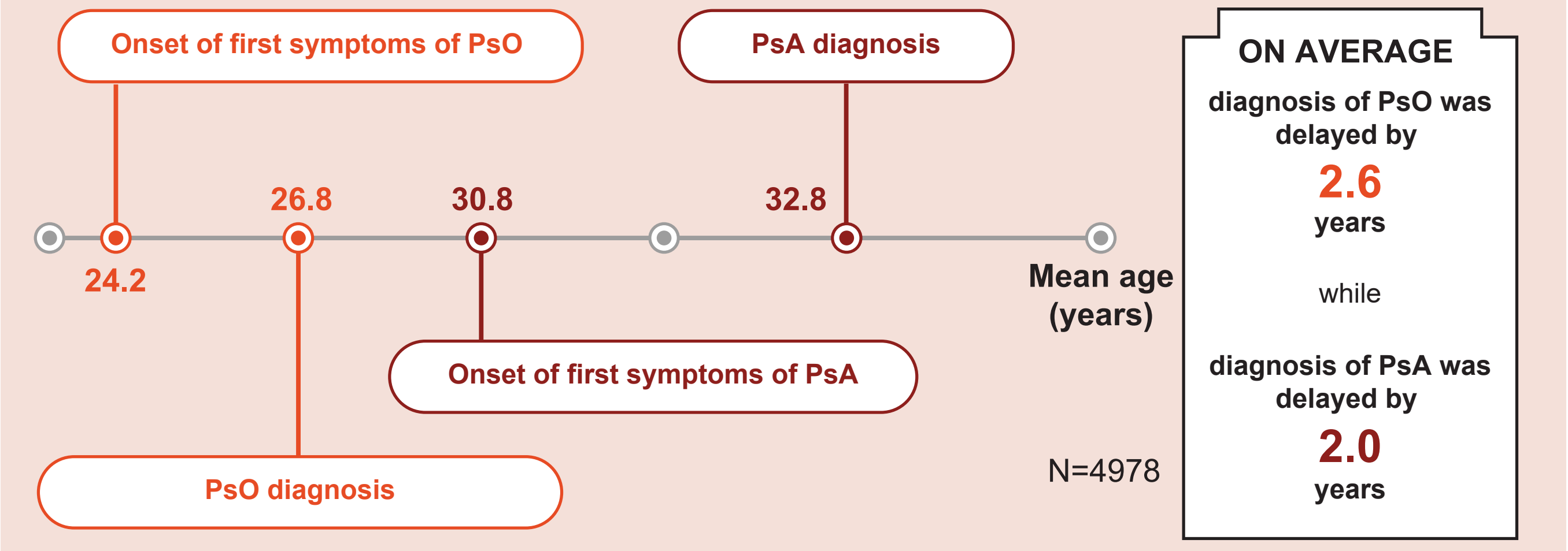
Patient's perceptions and attitudes related to the relationship with their health care professional

- Overall (N=4978), 59% of patients were not involved in deciding treatment goals
- The main treatment goals for HCPs and patients were to reduce the physical impact of disease and improvement of QoL

Patient's experience with diagnosis and treatment of the psoriatic disease

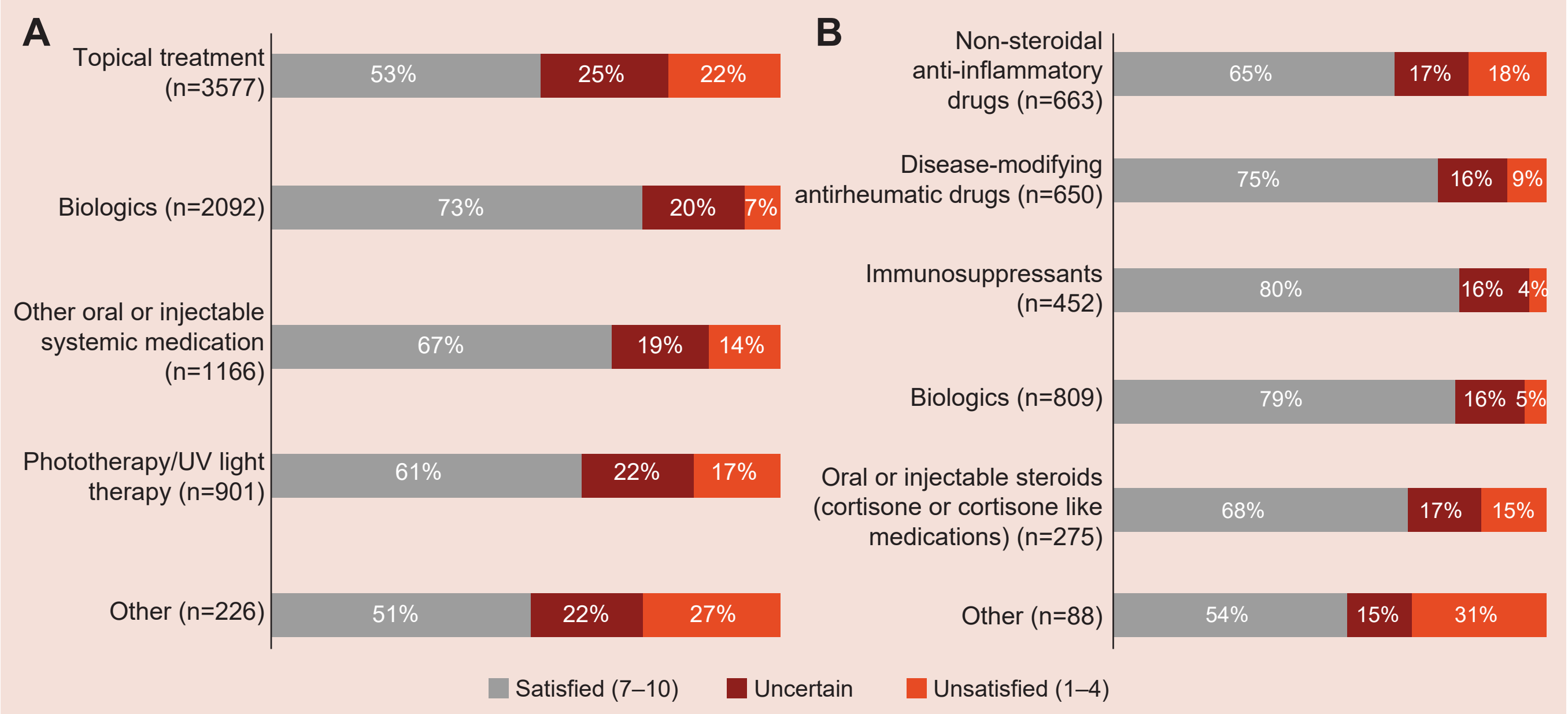
- On average, the confirmed diagnosis of PsO and PsA after first symptom was delayed by 2–3 and 2 years, respectively (**Figure 3**)
- Of 4757 patients with PsO and 1409 patients with PsA, 17% of PsO and 15% of PsA patients reported dissatisfaction with the current treatment, citing no improvement in QoL (47% each) and incomplete relief of skin (PsO: 54%) and joint (PsA: 43%) symptoms as primary reasons
- Most patients (PsO: 73%; PsA: 79%) were satisfied with biologics (**Figure 4**)

Figure 3. Delay in diagnosis of PsO and PsA from first symptoms



PsA, psoriatic arthritis; PsO, psoriasis.

Figure 4. Satisfaction with PsO (A) and PsA (B) treatments by current treatment



PsA, psoriatic arthritis; PsO, psoriasis.

Conclusions

- Results highlight that although many patients had heard the terms 'systemic disease' and 'psoriatic disease', they do not fully understand the systemic nature of their disease and therefore require further education
- Study findings show that PsD negatively impacted several aspects of patient's everyday life and their QoL
- Given the complexity and impact of PsD, early diagnosis and increasing patient participation in their care may facilitate shared decision-making between patients and HCPs, which along with providing personalized and holistic treatment strategy, may result in better overall patient outcomes

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2. Reich K, et al. *J Eur Acad Dermatol Venereol* 2020;34:1161–1173.

Disclosures

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