Patient Experiences with Psoriatic Disease in the United States: Results from the Psoriasis and Beyond Global Survey

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Synopsis

- Psoriatic disease (PsD) is a chronic, systemic, inflammatory illness affecting numerous body areas; it is associated with multiple comorbid conditions, substantial quality of life (QoL) impairment, and a high risk of depression[1,2]
- Assessing how much patients know about their disease and how PsD affects patients' everyday lives is important to improve PsD care; global surveys can provide valuable insights[3–5]
- The Psoriasis and Beyond Survey was conducted in partnership with IFPA, dermatology and rheumatology experts, and Novartis
- Findings from survey respondents based in the United States (US) are reported

Objective

- **Primary objective**: To assess patients' understanding of plaque psoriasis (PsO) and psoriatic arthritis (PsA) as part of a systemic condition, and the burden of PsD
- **Secondary objectives**: To assess patients' experiences with the healthcare system, including experiences with healthcare professionals (HCPs), timely diagnosis, and management

Methods

Study design and patients

- This was a cross-sectional, quantitative, online 25-minute survey of 793 US patients (≥18 years of age) with self-reported, physician-diagnosed, moderate-to-severe PsO, when it was at its worst, with or without concomitant PsA
  - Participants must have had moderate (≥5% to <10%) body surface area (BSA) involvement with PsO affecting hard-to-treat areas (face, palms, hands, fingers, genitals, soles of feet, or nails), or BSA ≥10% (severe), when PsO was at its worst
  - The survey was conducted between November 12, 2020, and May 19, 2021
- Patients were recruited through online panels by Institut de Publique Sondage d'Opinion Secteur (Ipsos SA) and patient advocacy groups (organized/coordinated by IFPA and Novartis), and were screened for eligibility via a 5-minute questionnaire
- Validated tools (e.g., Dermatology Life Quality Index [DLQI] and the Psoriasis Epidemiology Screening Tool [PEST]) plus questions outside these tools (reviewed by the Steering Committee) were included in the survey

Results

Baseline demographics and clinical characteristics

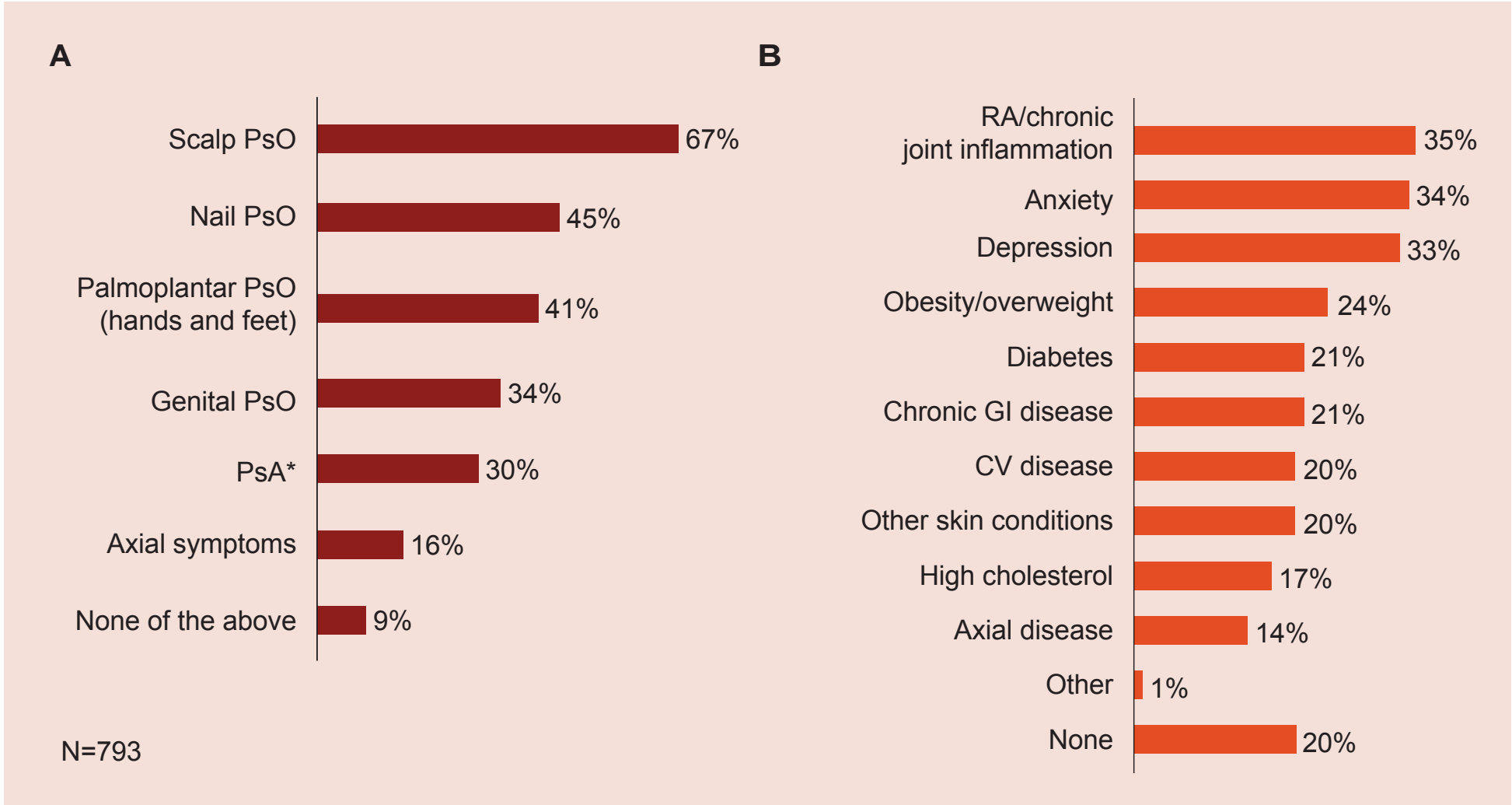
- Of the 793 respondents, 52% were women and 48% were men (average age 44.6 and 42.8 years, respectively)
- Overall, 64% of respondents had moderate PsO and 36% had severe PsO at its worst; 43% had concomitant PsA
  - Of the respondents without a diagnosis of PsA (n=450), 50% screened positive for PsA using the PEST

PsD manifestations and comorbidities

Respondents' awareness and understanding of PsD

- Most respondents had heard the term 'psoriatic disease' (65%) and were aware that their condition was a systemic disease (75%)
- On average, respondents were aware of 2.6 common PsD manifestations (**Figure 1A**) and 3.0 comorbidities (**Figure 1B**)

Figure 1: Proportion of respondents aware of (A) the manifestations related to PsD and (B) the associated comorbidities

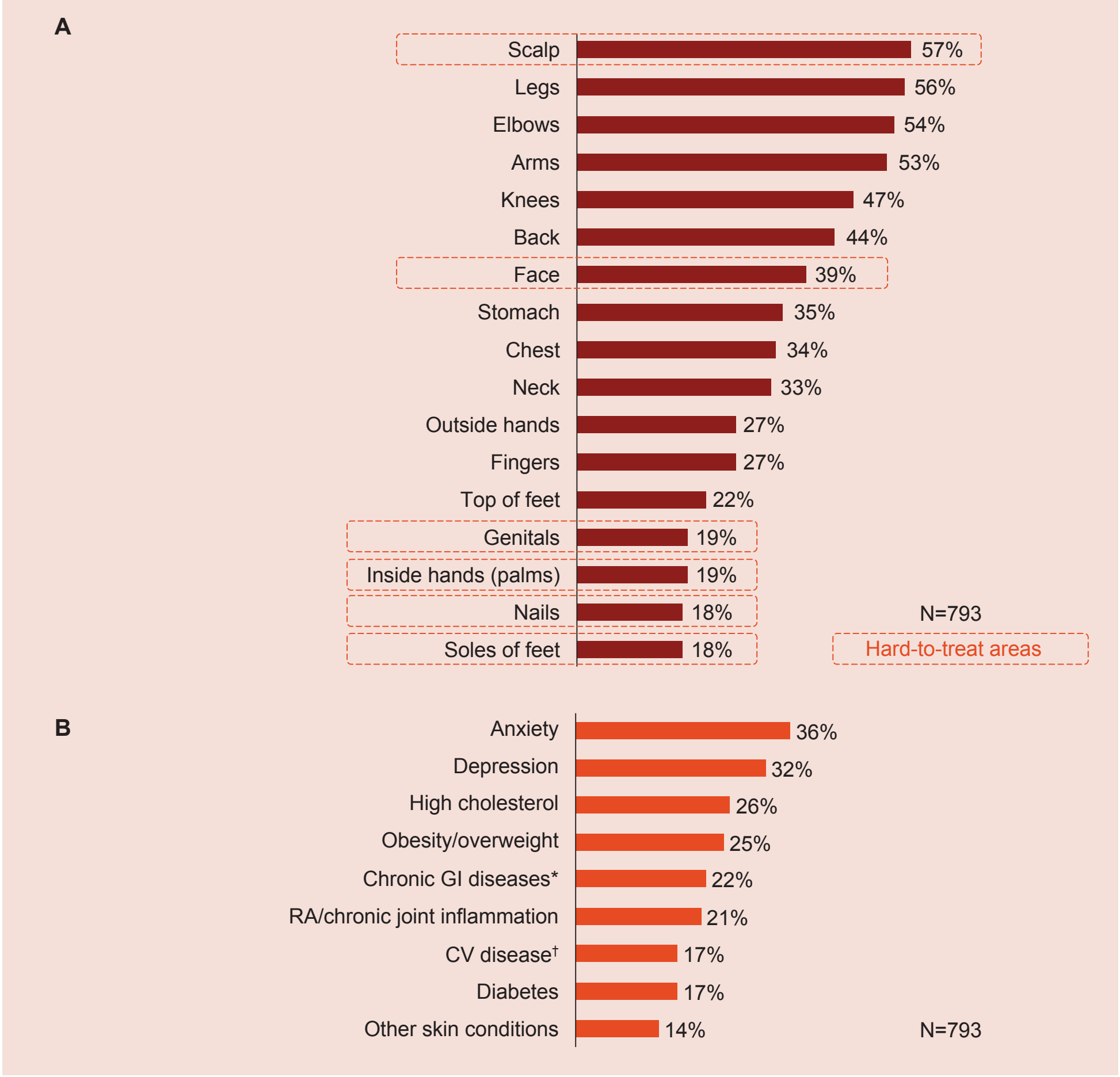


*Only shown to respondents without concomitant PsA.
CV, cardiovascular; GI, gastrointestinal; PsA, psoriatic arthritis; PsD, psoriatic disease; PsO, psoriasis; RA, rheumatoid arthritis.

Respondents' experience of PsD manifestations and comorbidities

- At the time of survey, 48% of respondents had mild PsO (BSA <5%), 32% had moderate PsO (BSA ≥5% to <10%), and 20% had severe PsO (BSA ≥10%), with 6 body parts affected on average (**Figure 2A**)
- Respondents with PsA (n=343) reported swollen and tender joints, especially in the finger(s) and/or toe(s), as the most common symptom (77%)
- Respondents reported 2.7 diagnosed comorbidities, on average (**Figure 2B**)

Figure 2: Proportion of respondents with (A) body parts affected by PsO at the time of survey and (B) diagnosed comorbidities

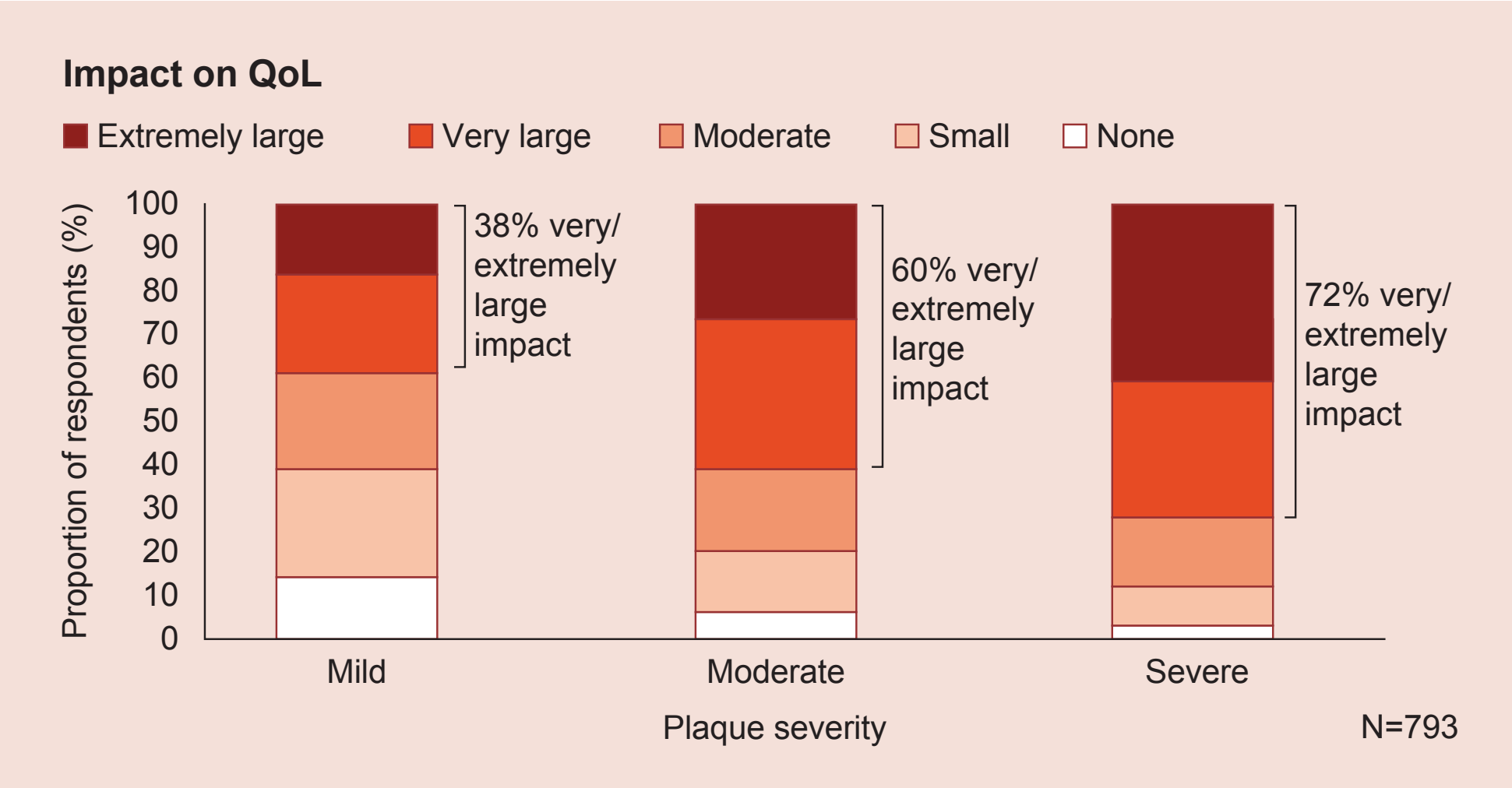


*For example, irritable bowel syndrome, indigestion, ulcerative colitis, Crohn's disease, heartburn, gastritis; †For example, cardiac/heart failure, arrhythmia, cardiomyopathy, coronary artery disease, hypertension; CV, cardiovascular; GI, gastrointestinal; PsO, psoriasis; RA, rheumatoid arthritis.

Burden of PsD on QoL

- QoL was affected even in patients with mild disease (**Figure 3**)

Figure 3: Impact of PsD on QoL by plaque severity using DLQI

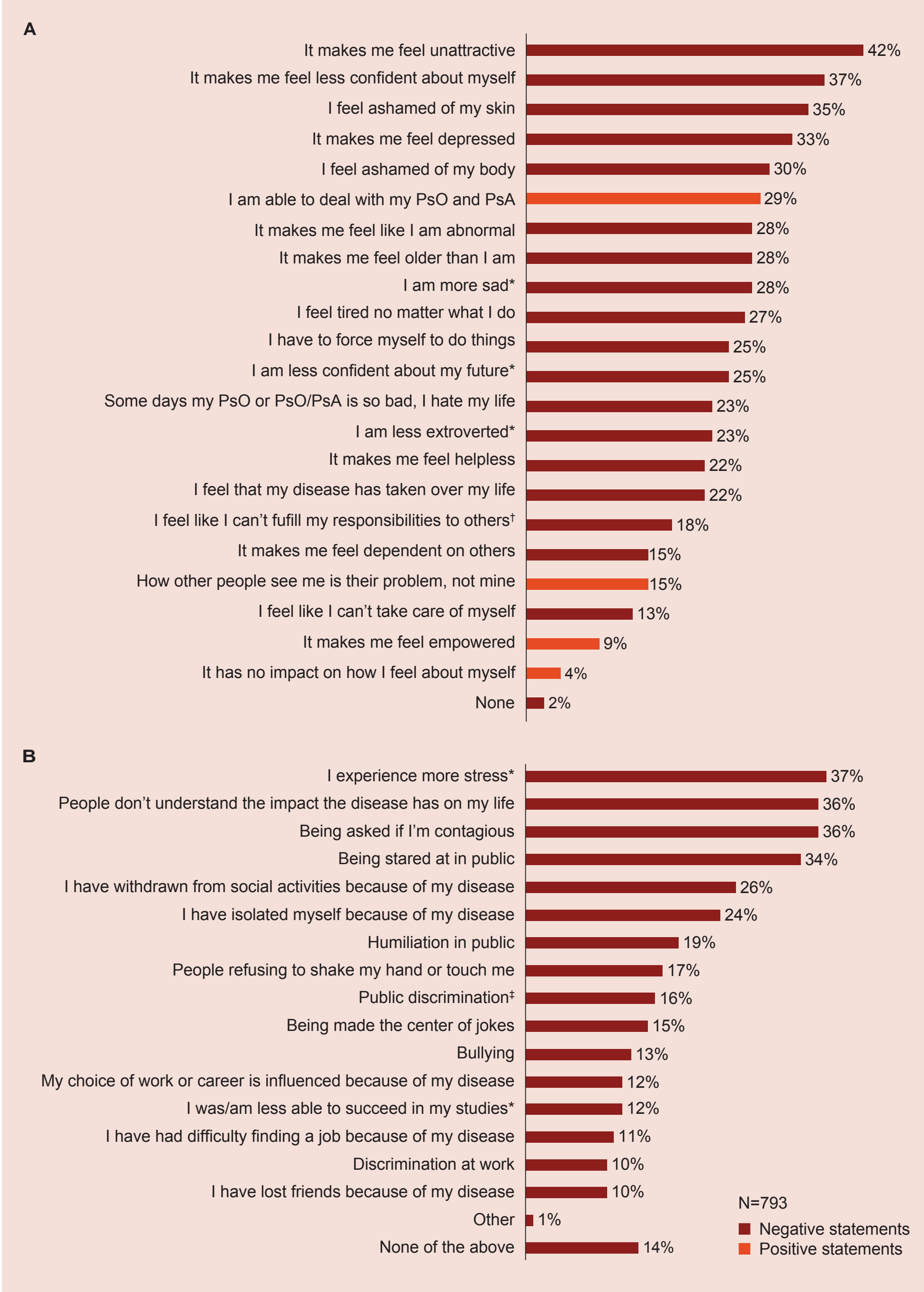


Data shown for current plaque severity. Mild: BSA <5%; moderate: BSA ≥5% to <10%; severe: BSA ≥10%.
BSA, body surface area; DLQI, Dermatology Life Quality Index; PsD, psoriatic disease; QoL, quality of life.

Impact of PsD on emotional wellbeing

- Positive and negative emotions were associated with living with PsD (**Figure 4A**)
- Only 14% of all respondents had not experienced stigma or discrimination due to PsD (**Figure 4B**)

Figure 4: Proportion of respondents experiencing (A) emotional impact of PsD and (B) stigma and discrimination due to PsD

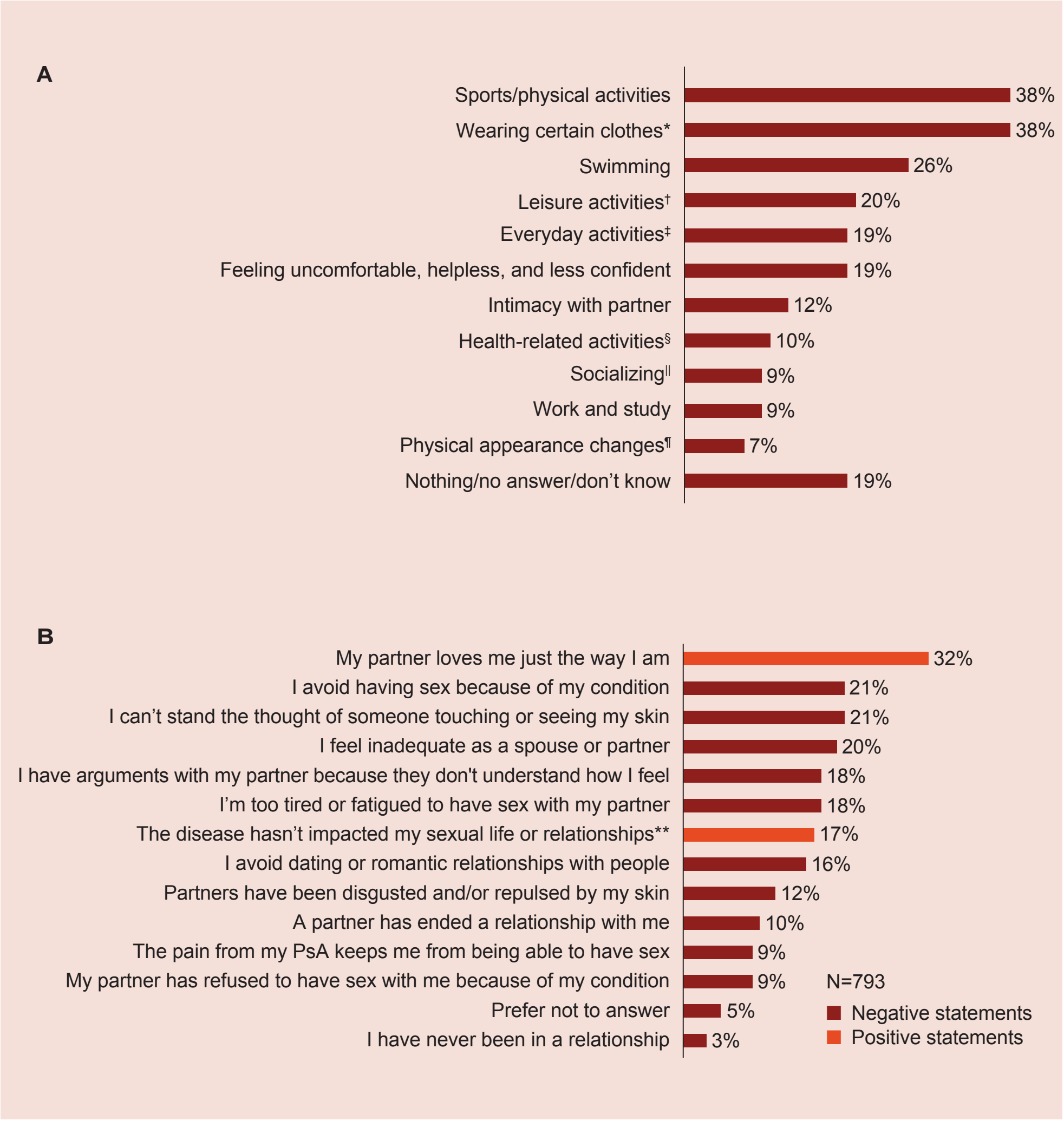


*Compared to without disease; †Including caring for children, grandchildren, partner, employment (paid and unpaid), including any impact of dependence on others; ‡For example, refusal to provide treatment at a beauty clinic, people refusing to serve me in shops, and being asked to leave public transport.
PsA, psoriatic arthritis; PsD, psoriatic disease; PsO, psoriasis.

Burden of PsD on work, activities, and relationships

- One third of respondents (29%) could not go to work at all during the previous week due to PsD skin manifestations
- Respondents felt unable to take part in activities (**Figure 5A**) and reported that the disease impacted personal relationships (**Figure 5B**)

Figure 5: Proportion of respondents reporting impact of PsD on (A) activities and (B) relationships



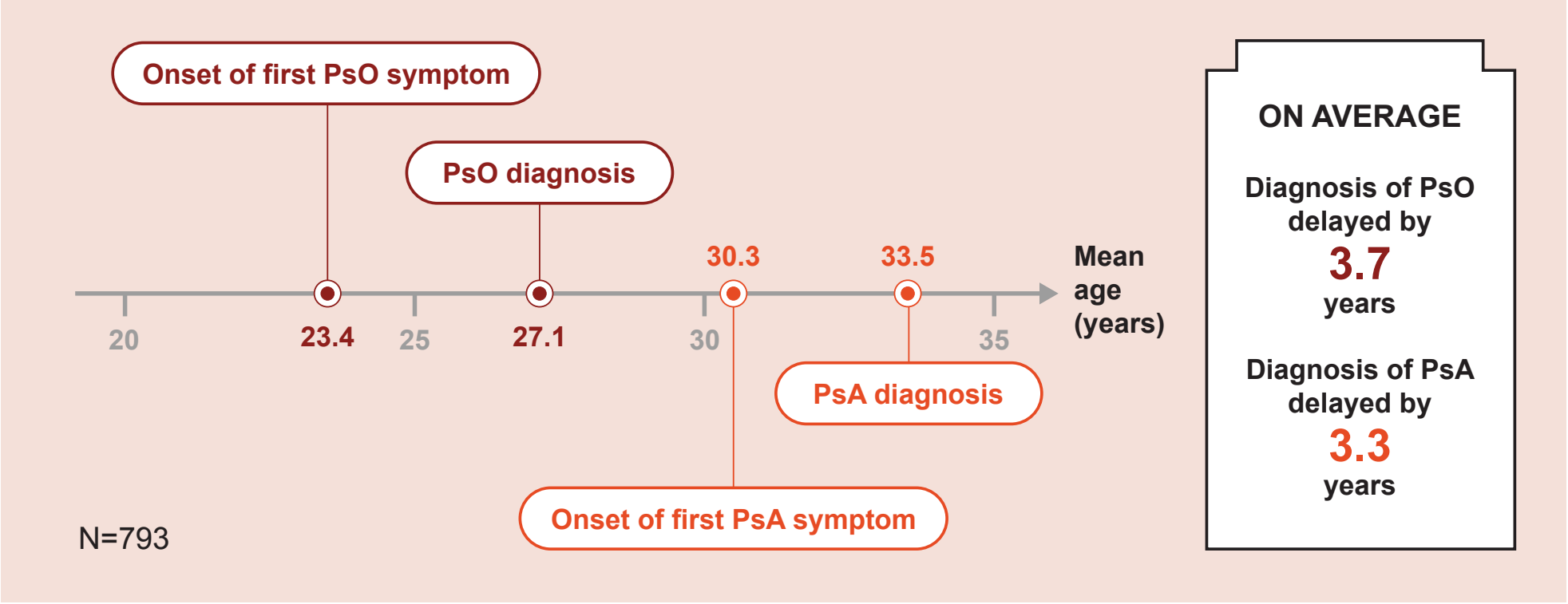
*Such as wearing low-cut clothes, exposing my body/skin more, wearing swimsuit/bikini, wearing open shoes/without socks; †Such as travel, going out, dancing, taking a trip; ‡Such as shopping, going for a walk, sleeping well; §Such as not taking medication/not caring about medicating myself, being healthy/not having psoriasis; ‖Including meeting friends, playing with (grand-)children, going to parties, etc.; ¶Such as wearing makeup, going to hairdresser; **With my current/ previous spouse or partner. PsA, psoriatic arthritis; PsD, psoriatic disease.

Respondents' experiences with the healthcare system

Respondents' experience with diagnosis

- On average, PsO diagnosis was delayed by 3.7 years and PsA diagnosis was delayed by 3.3 years from symptom onset (**Figure 6**)

Figure 6: Delay in PsO and PsA diagnosis after symptom onset



PsA, psoriatic arthritis; PsO, psoriasis.

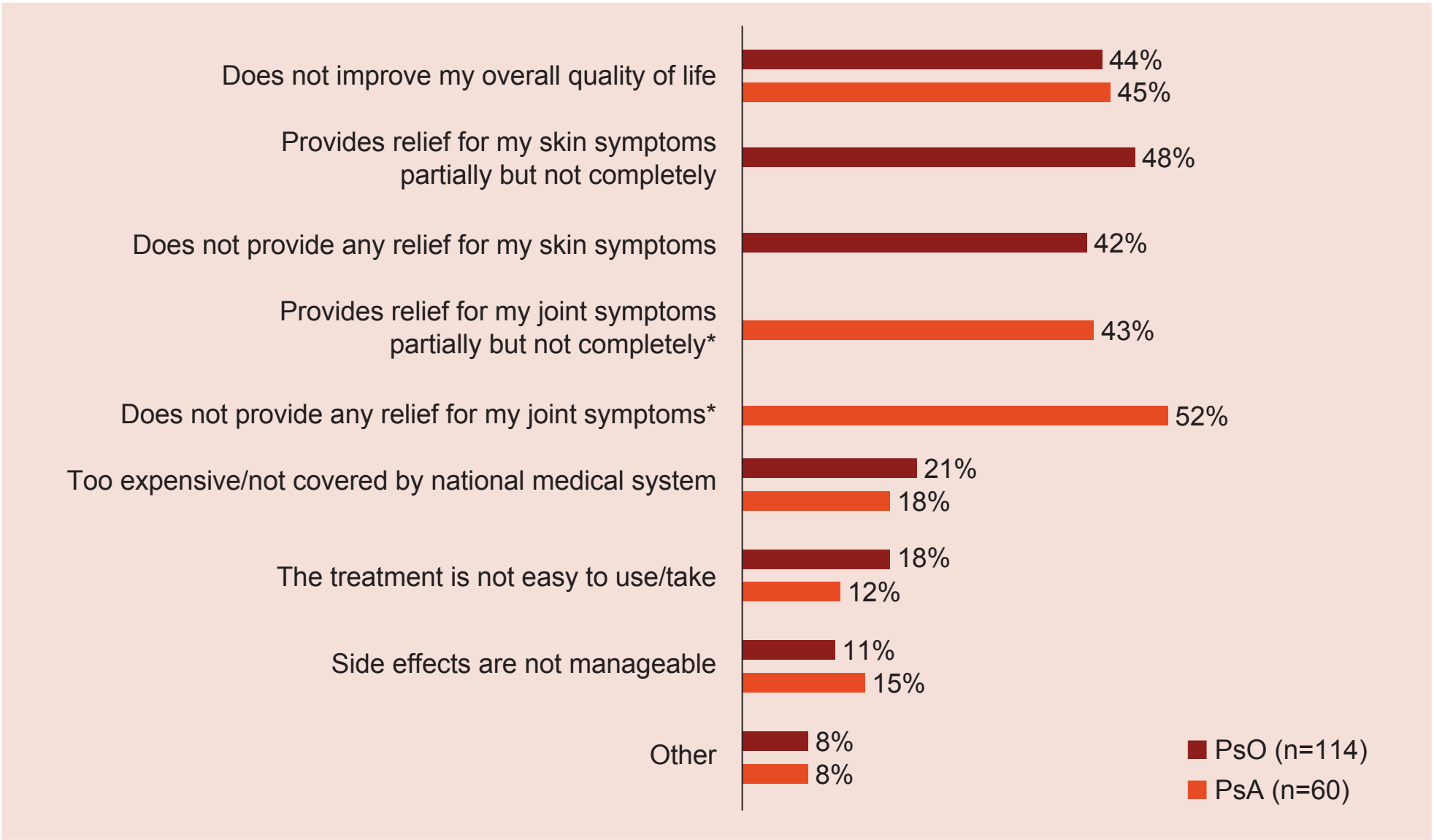
Respondents' perspectives on their relationships with HCPs

- Around half of respondents (51%) discussed treatment goals with HCPs
- Main goals agreed with HCPs were to reduce skin symptoms (52%) and to improve QoL (48%)

Respondents' perspectives on PsD management

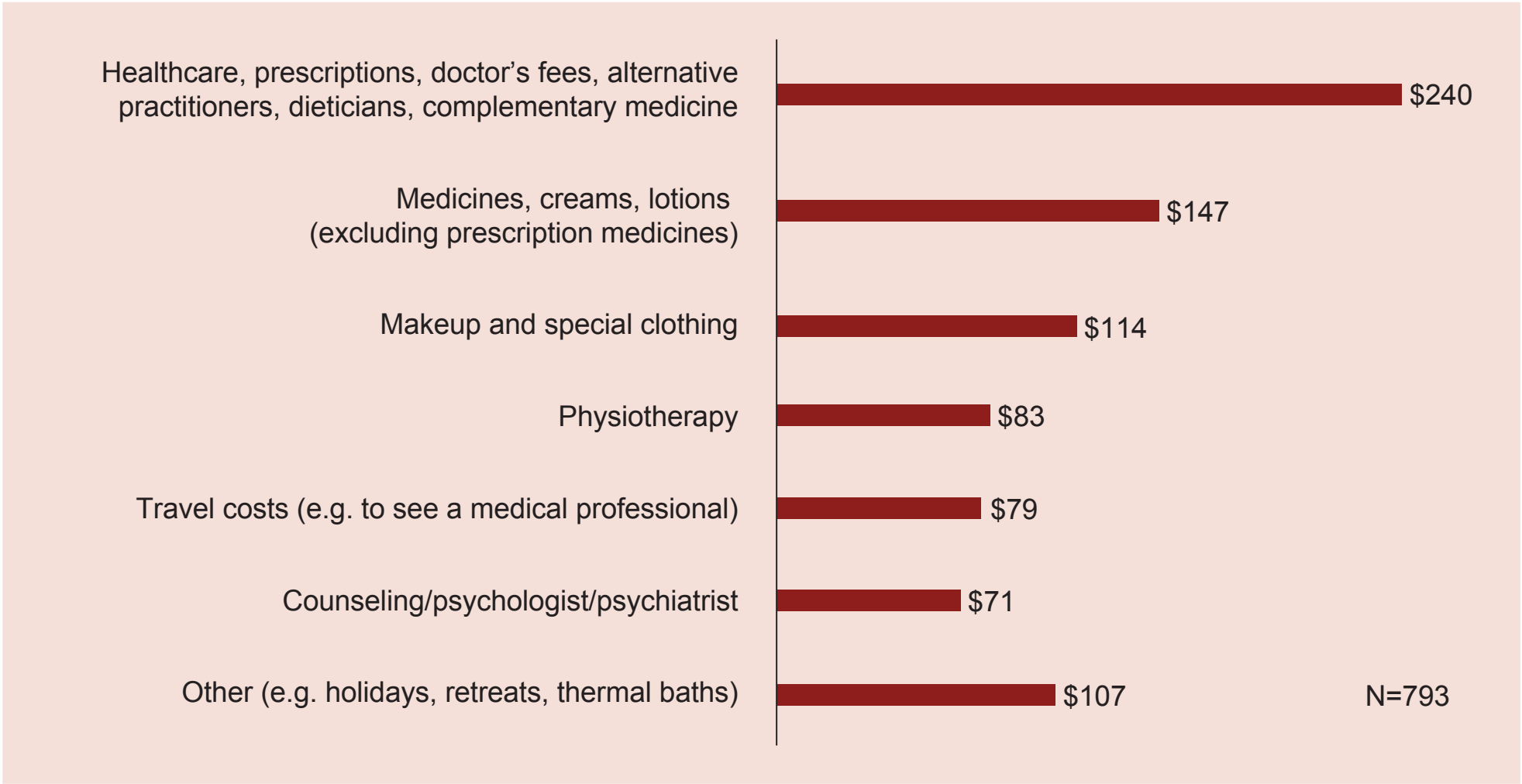
- Most respondents were currently using topical therapy (73%) and/or biologics (56%) for their PsO
  - The mean number of topical therapies received during the course of the disease was 4.1
  - The mean number of biologics received during the course of the disease was 2.7
  - Some respondents (35%; n=278) refused biologics despite HCP recommendation; the most common reasons were possible side effects (45%), long-term effects (38%), and out-of-pocket costs (37%)
- Most respondents (PsO: 58%; PsA: 61%) experienced either no change in or a worsening of their condition with their current treatment at the time of survey
- Some respondents (PsO: 15%; PsA: 18%) were dissatisfied with their current treatment (**Figure 7**)
- Respondents reported spending their own money on several aspects of their condition (**Figure 8**)

Figure 7: Proportion of respondents reporting reasons for dissatisfaction with current treatment



*Only shown to respondents with concomitant PsA.
PsA, psoriatic arthritis; PsO, psoriasis.

Figure 8: Mean monthly out-of-pocket costs for PsD in US Dollars



PsD, psoriatic disease.

Conclusions

- PsD may be underdiagnosed in the US; half of patients without a PsA diagnosis screened positive on the PEST questionnaire, indicative of potential PsA
- Patients with PsD have inadequate awareness of common PsD manifestations and systemic comorbidities, highlighting an unmet need for patient education
- Even mild PsD has a substantial impact on patient QoL, emotional wellbeing, relationships, and activities. Most patients experience stigma and discrimination[5]
- Patients face a complex journey through healthcare systems, experiencing delayed diagnosis and dissatisfaction with treatment
- To manage this long-term systemic disease effectively and improve patients' emotional wellbeing, a holistic approach to PsD management beyond controlling skin symptoms should be adopted

Disclosures

AA serves as research investigator and/or scientific advisor to AbbVie, Boehringer Ingelheim, Bristol Myers Squibb, EPI, Incyte, Leo, UCB, Janssen, Eli Lilly, Novartis, Ortho Dermatologics, Sun, Dermavant, Dermira, Sanofi, Regeneron, and Pfizer. LCC has received grants/research support from AbbVie, Amgen, Celgene, Eli Lilly, Janssen, Novartis, Pfizer and UCB; worked as a paid consultant for AbbVie, Amgen, Boehringer Ingelheim, Bristol Myers Squibb, Celgene, Eli Lilly, Gilead, Galapagos, Janssen, Moonlake, Novartis, Pfizer and UCB; and has been paid as a speaker for AbbVie, Amgen, Biogen, Celgene, Eli Lilly, Galapagos, Gilead, GSK, Janssen, Medac, Novartis, Pfizer and UCB. BB, SM, and SFB do not have any conflicts of interests. GG is an employee of the National Psoriasis Foundation. MA has served as consultant for/or has been a paid speaker for clinical trials sponsored by companies that manufacture drugs used for the treatment of psoriasis, including AbbVie, Almirall, Amgen, Biogen, Boehringer Ingelheim, Celgene, Centocor, Eli Lilly, GSK, Janssen-Cilag, Leo, Medac, Merck, MSD, Novartis, Pfizer, UCB, and Xenoport. AO has served as a consultant for AbbVie, Amgen, Bristol Myers Squibb, Celgene, CorEvitas, Gilead, GSK, Janssen, Eli Lilly, Novartis, Pfizer, UCB and has received grant funding to the University of Pennsylvania from AbbVie, Novartis and Pfizer and to the National Databank for Rheumatic Diseases (FORWARD) databank from Amgen. EK, MK, and SF are full-time employees at Novartis Pharma AG, Basel, Switzerland.

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