CLINICAL REPORT

Prevalence of Psoriasis and Psoriatic Arthritis and Patient Perceptions of Severity in Sweden, Norway and Denmark: Results from the Nordic Patient Survey of Psoriasis and Psoriatic Arthritis

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Optimal clinical management of psoriasis and psoriatic arthritis (PsA) requires understanding of the impact on patients. The NORdic PAtient survey of Psoriasis and PsA (NORPAPP) aimed to obtain current data on disease prevalence and patient perceptions in Sweden, Denmark and Norway. Among 22,050 individuals questioned, the reported prevalence of psoriasis and/or PsA was 9.7% (5.7% physician-diagnosed plus 4.0% self-diagnosed only); prevalence was similar in Sweden (9.4%) and Denmark (9.2%) but significantly higher in Norway (11.9%). Of those reporting a physician's diagnosis, 74.6% reported psoriasis alone, 10.3% PsA alone and 15.1% both. Patients with PsA perceived their disease to be more severe than those with psoriasis; patients with PsA and psoriasis reported greater disease severity than those with each condition alone. Patient's perceptions of psoriasis severity correlated weakly (Spearman's rho 0.42) with clinical severity; both patient perceptions and clinical measures are important in the assessment and management of psoriasis.

Key words: psoriasis; psoriatic arthritis; severity; prevalence; diagnosis.

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SIGNIFICANCE

The NORdic PAtient survey of Psoriasis and Psoriasis arthritis (NORPAPP) collected data on disease prevalence and patient perceptions in Sweden, Denmark and Norway. Among 22,050 individuals questioned, the reported prevalence of psoriasis and/or psoriatic arthritis was 9.7% (5.7% physician-diagnosed plus 4.0% self-diagnosed only). Of patients with a physician's diagnosis, 74.6% reported psoriasis alone, 10.3% psoriatic arthritis alone and 15.1% both. Patients with psoriatic arthritis perceived their disease to be more severe than those with psoriasis; patients with psoriatic arthritis and psoriasis reported greater disease severity than those with each condition alone. Psoriasis is common and has a large impact on patient's life.

Psoriasis (PsO) is a chronic, immune-mediated, inflammatory skin condition that can have a major impact on a patient's health-related quality of life (HRQoL) (1). Estimates of the global prevalence of PsO in adults span a wide range (0.5–11.4%) and published figures vary according to the region (lower in Asia, higher in Europe), the population studied (general population, hospital cohort, patient registry) and the diagnosis and reporting method (2, 3). Estimates from studies in Norway, Sweden and Denmark suggest a relatively high prevalence of PsO in the Scandinavian region (2.2–11.4%) (4–10). Approximately 30–35% of individuals with PsO can also develop painful joint inflammation, known as psoriatic arthritis (PsA) (11–14). The timing of PsA symptoms is very variable, although PsA often manifests approximately 10 years after the initial appearance of psoriasis symptoms on the skin (11) it can also precede them.

In addition to controlling the clinical manifestations of PsO and PsA, optimal clinical management of these conditions requires a clear understanding of the impact of the disease on individual patients, taking into consideration their own perception of severity and treatment success (15, 16). Numerous small patient surveys (summarized by Lebwohl et al. in 2014 (17)) carried out over the past 50 years have provided useful information about the prevalence and treatment of PsO, but few were population-based and many lacked information on patient perceptions. To address this gap, the Multinational Assessment of Psoriasis and Psoriatic Arthritis (MAPP) survey was carried out in 2012 (17). While the MAPP survey provided much valuable information, it excluded the Nordic countries.

The NORdic PAtient survey of Psoriasis and Psoriatic arthritis (NORPAPP) was conducted to gain a better understanding of patients with PsO and PsA in Sweden, Denmark and Norway. The purpose of the NORPAPP was to provide some insight into the main challenges faced by people living with PsO and PsA in these countries and to understand the patients' perspectives on their disease, communication with the healthcare system and the different treatments prescribed. In this paper, we describe the NORPAPP survey population and results relating to disease diagnosis, prevalence and

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patient perceptions of disease severity and extent. Future publications will describe the results relating to quality of life and contact with healthcare systems, and treatment use and patient satisfaction.

METHODS

Survey population

The survey was carried out by the market research firm YouGov during November and December 2015 using YouGov panels in Sweden, Denmark and Norway following the International Chamber of Commerce (ICC)/European Society for Opinion and Marketing Research (ESOMAR) International Code on Market, Opinion and Social Research and Data Analytics. The survey was conducted in accordance with ethical standards required in each participating country.

YouGov panels are made up of a wide cross-section of individuals who have specifically opted in to participate in online studies (YouGov incentivizes participation by awarding points that can be redeemed for goods or entry to prize draws). An initial survey population was randomly selected from the YouGov panels using framing quotas based on the population census data to ensure inclusion of a representative sample of adults (aged 18–74 years) from each country. Quotas were set on the variables age, sex and region. The initial survey population was representative of these variables both overall and within each variable.

The initial survey population were contacted by email and asked to select 1 of 4 possible responses to the question "Do you have any type of psoriasis or psoriatic arthritis?": "Yes, and I am diagnosed by a physician", "Yes, but I am not diagnosed by a physician", "No, I don't have any type of psoriasis" or "Don't know/do not wish to answer". Based on the response to this question, the target survey population (men and women aged 18–74 years who indicated that they had been diagnosed with PsO and/or PsA by a physician) were invited to participate in the full survey.

Survey design

E-mail invitations were sent to the target survey population and respondents filled in their questionnaire answers online via an online link. The questionnaire included 44 questions covering perceived severity and symptoms, quality of life, contact with the healthcare system and treatment and medications. The full list of questions can be found in Appendix S1[1].

Severity

The survey incorporated 2 questions that measured severity, one based on the respondents' perception and 1 based on the area of PsO. Respondents with PsO alone and with PsO + PsA were asked to rate their disease on a 5-point scale from "not severe at all" to "extremely severe". For analyses of the relationships between severity and other factors, the respondents' reported 5-level self-perception of severity was dichotomized to non-severe ("not severe at all" or "not particularly severe") and severe ("quite severe", "very severe" or "extremely severe"). Respondents were also asked to estimate the total area of their PsO symptoms, using the area of their own palms as a measurement unit, within the ranges: 0, 1–3, 4–9, 10–19 and ≥20 palms. These data were then used to define estimates of conventional clinical severity by assuming that the area of 1 palm=1% of body surface area (BSA): mild (≤3% BSA), moderate (4–9% BSA) and severe (≥10 % BSA).

[1]https://www.medicaljournals.se/acta/content/abstract/10.2340/00015555-3017

Statistical analysis

Data from the 3 countries were analysed together as a pooled dataset. Descriptive statistics were used to summarize demographic information for the surveyed population. The final survey data were weighted to the national profile of all adults within the included age group. Sample subpopulations were weighted to match national sex and age distributions.

Significant deviations in responses between subgroups based on country, diagnoses, age, sex and patient organization membership were assessed using the χ^2 test and z-test with Bonferroni correction (total $\alpha=0.05$) for comparisons of multiple answers within each question.

RESULTS

Study population

A total of 22,050 individuals were questioned about PsO and PsA: 87.4% responded that they did not have PsO or PsA; 9.7% reported having PsO and/or PsA (Sweden, 9.4%; Denmark, 9.2%; Norway, 11.9%), which included 5.7% that were physician-diagnosed and 4.0% that were self-diagnosed only (**Table I**). The proportions of responses were broadly comparable across countries, although the prevalence of physician-diagnosed PsO and/or PsA reported by Norwegian respondents was significantly higher than that reported by Swedish respondents. The prevalence of self-diagnosed PsO and/or PsA was also significantly ($p<0.05$) higher for Norwegian respondents than for both Danish and Swedish respondents. The proportion of respondents that reported having self-diagnosed PsO and/or PsA was lower in the older age group (45–74 years; 33%) than in the younger age group (18–44 years; 48%).

All individuals who reported physician-diagnosed PsO and/or PsA were invited to participate in the full survey and 1,221 (96.6%) responded. Population demographics and disease states are provided in Table I. There were approximately equal numbers of male and female respondents, but slightly more older than younger respondents. Membership of a patient organization was reported by 21.0% of respondents overall; a greater proportion of patients with PsA ± PsO were members of patient organizations compared with patients with PsO alone.

Diagnosis

Overall, for the pooled data set, PsO alone was the most frequently reported diagnosis, with fewer respondents reporting a diagnosis of PsA alone or combined PsA + PsO (Table I). The estimated prevalence of physician-diagnosed PsO was 5.1% and that of PsA was 1.5%. In Denmark, there was a significantly ($p<0.05$) higher proportion of respondents reporting PsO alone and a significantly ($p<0.05$) lower proportion of respondents reporting of PsA + PsO compared with Sweden and Norway (Table I). Within the pooled population of respondents, a significantly ($p<0.05$) higher proportion of

Table I. Demographics of base population (with responses to the initial survey question "Do you have any type of psoriasis or psoriatic arthritis?", which had 4 mutually exclusive answer options: "Yes, and I'm diagnosed by a physician"; "Yes, but I'm not diagnosed by a physician"; "No, I don't have any type of psoriasis"; "Don't know/do not wish to answer") **and demographics and disease states of the population reporting physician-diagnosed PsO/PsA who responded to the extended survey. Base numbers were weighted to match national distributions of sex and age.**

	Total	Sweden	Denmark	Norway
Total number asked about PsO/PsA, N_{Tot}	22,050	9,781	8,871	3,398
Female (unweighted), *n*	10,922 (11,243)	4,831 (4,661)	4,426 (4,778)	1,665 (1,804)
Male (unweighted), *n*	11,128 (10,807)	4,950 (5,120)	4,445 (4,093)	1,733 (1,594)
Aged 18–44 years (unweighted), *n*	10,795 (9,193)	4,819 (3,934)	4,229 (3,606)	1,747 (1,653)
Aged 45–74 years (unweighted), *n*	11,255 (12,857)	4,962 (5,847)	4,642 (5,265)	1,651 (1,745)
Diagnosed by a physician (invited to answer more questions), % of N_{Tot} (*n*)	5.7 (1,264)	5.3 (521)[a]	5.8 (513)[a,b]	6.8 (230)[b]
Female, %	51.6	51.2	53.4	48.2
Aged 18–44 years/45–74 years, %	44.8/55.2*	44.4/55.6	43.6/56.4	48.4/51.6
Self-diagnosed only, % N_{Tot} (*n*)	4.0 (875)	4.1 (388)[a]	3.4 (305)[a]	5.1 (174)[b]
Female, %	45.3*	47.1	44.0	43.5
Aged 18–44 years/45–74 years, %	60.0/40.0*	59.4/40.6	59.8/40.2	61.5/38.5
Do not have PsO or PsA, % N_{Tot} (*n*)	87.4 (19,275)	87.8 (8,587)[a]	88.5 (7,854)[a]	83.4 (2,834)[b]
Female, %	49.9*	49.7	50.2	49.7
Aged 18–44 years/45–74 years, %	48.3/51.7*	48.6/51.4	47.2/52.8	50.3/49.7
No answer, % N_{Tot} (*n*)	2.9 (636)	2.8 (277)[a]	2.2 (198)[b]	4.7 (161)[c]
Female, %	39.2*	39.5	35.8	42.7
Aged 18–44 years/45–74 years, %	63.3/36.7*	65.3/34.7	59.7/40.3	64.3/35.7
Invited participants who responded, % N_{Tot} (*n*)	1,221 (96.6)	497 (95.4)	506 (98.5)	218 (94.8)
Female, %	51.1	50.3	53.2	47.9
Aged 18–44 years/45–74 years, %	44.9/55.1	44.8/5.2	43.6/56.4	48.2/51.8
Member of patient group, %[d]	21.0	22.5[a]	17.9[b]	24.5[a]
Only psoriasis, *n* (%)	911 (74.6)	342 (68.8)[a]	411 (81.2)[b]	158 (72.6)[a]
Female, %	50.6	50.8	52.8	44.5
Aged 18–44 years/45–74 years, %	45.7/54.3	45.9/54.1	44.7/55.3	47.8/52.2
Member of patient group, %[d]	14.6	17.2	11.0	18.6
Only psoriatic arthritis, *n* (%)	126 (10.3)	56 (11.3)[a]	41 (8.1)[a]	29 (13.4)[a]
Female, %	46.7	52.1	39.2	46.8
Aged 18–44 years/45–74 years, %	51.3/48.7	50.3/49.7	45.6/55.4	61.3/38.7
Member of patient group, %[d]	46.5	39.4	51.6	52.5
Both psoriasis and psoriatic arthritis, *n* (%)	184 (15.1)	99 (19.9)[a]	54 (10.8)[b]	31 (14.0)[a,b]
Female, %	56.2	47.5	66.4	66.2
Aged 18–44 years/45–74 years, %	36.7/63.3*	38.1/61.9	33.7/66.3	37.8/62.2
Member of patient group, %[d]	35.3	32.5	45.0	27.5

[a,b,c]Within each row where the data between 2 countries does not differ significantly, the data in each country column is marked with the same letter. Different letters within the row indicate where data for countries does differ significantly (Bonferroni corrected z-test, total α=0.05). [d]Denominators for "member of patient group" % were lower as some respondents did not answer.
*Denotes a significant difference between sex or age-range subgroups within the total of participants (Bonferroni corrected z-test, total α=0.05).

those with PsA + PsO were in the older age group (45–74 years). Membership of a patient organization was more common among respondents with PsA and PsA + PsO than among those with PsO alone.

A significantly ($p < 0.05$) higher proportion of respondents with PsO alone were diagnosed within one year of first noticing symptoms compared with respondents diagnosed with PsA alone (**Fig. 1**a). Twice as many respondents reporting PsA alone had a delay of 10 years or more before they were diagnosed compared with respondents reporting PsO alone. The pattern was similar for respondents with PsA + PsO (Fig. 1b). Just over a third of respondents (39.3%) with PsA + PsO were diagnosed for each condition within the same elapsed time after the occurrence of symptoms, but more respondents (44.1%) had shorter delays for the diagnosis of PsO than for PsA and a few (16.6%) had shorter delays for the diagnosis of PsA than for PsO.

Psoriasis

Severity. Most respondents with PsO alone (72.7%) considered their condition to be "not severe at all" or "not particularly severe" (**Fig. 2**a). Relative to respondents with PsO alone, there were significantly ($p < 0.05$) higher proportions of respondents with PsO + PsA who considered their condition to be "quite severe" or "very severe". The proportion of respondents with PsO alone considering their condition to be severe were higher among members of patient organizations compared with non-members (49.2% vs. 23.3%, $p < 0.05$). PsO severity based on the estimated % BSA involved showed a similar pattern (Fig. 2b). The 2 severity measures correlated moderately (Spearman's rank correlation 0.42) (**Table II**).

Symptoms. Flare-ups of PsO were reported to occur quarterly or more often by 61.1% of respondents and every 6 months or less often by 33.8% of respondents (the question defined flare-ups as "periods when symptoms have worsened"). Common locations of PsO symptoms were the scalp and the elbow (**Table III**). Several locations were affected in a significantly ($p < 0.05$) greater proportion of respondents with PsO + PsA compared with PsO alone (Table III). PsO symptoms at most locations were reported by a significantly ($p < 0.05$) greater proportion of respondents who perceived their symptoms to be severe ("quite severe" or worse) vs. non-severe ("not particularly severe" or better) (**Table IV**). The most common

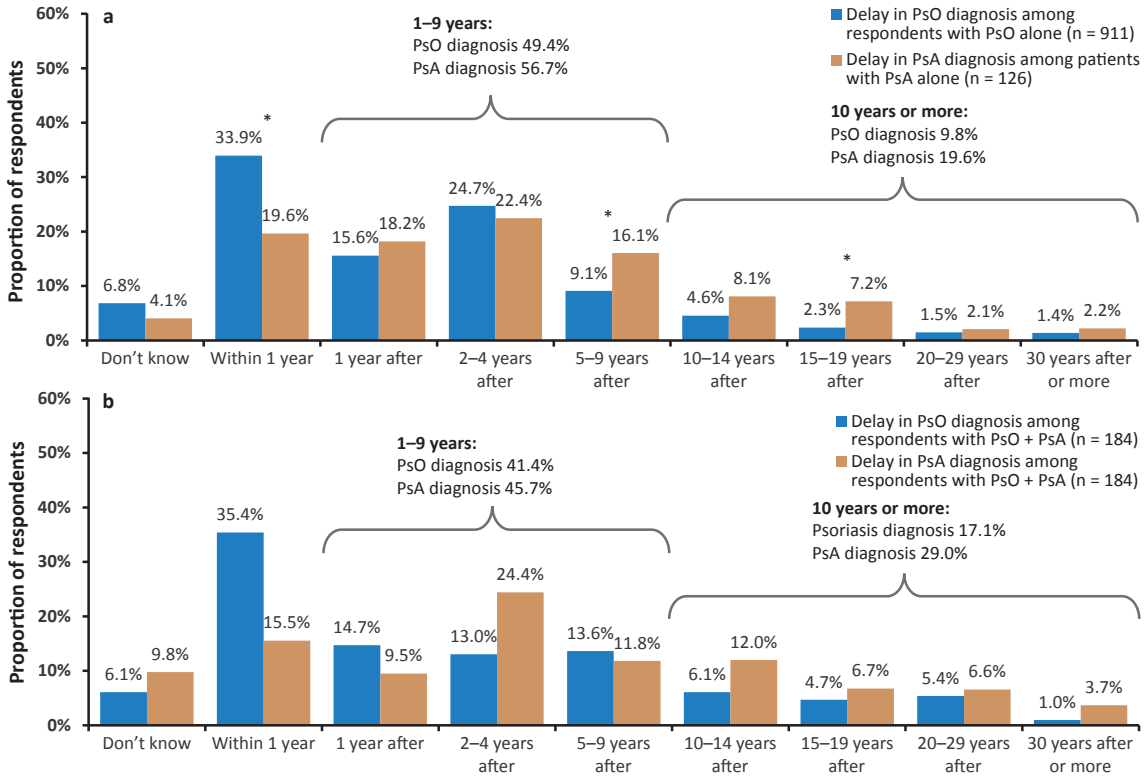

Fig. 1. Delay in diagnosis from the onset of symptoms for respondents: (a) reporting psoriasis (PsO) alone vs. those reporting psoriatic arthritis (PsA) alone; and (b) reporting both PsA and PsO. *Significant difference between PsO and PsA groups (Bonferroni corrected z-test, total α=0.05).

PsO-related symptoms equally affecting those with PsO alone and those with both PsO + PsA were flaking/scales and itching (**Fig. 3**). Most of the less frequent symptoms of PsO, which are also commonly associated with PsA (e.g. dactylitis, enthesitis), were reported at significantly ($p < 0.05$) and substantially greater rates by respondents with PsO + PsA, as expected (Fig. 3).

The 2 most common symptoms were reported significantly more often in respondents whose symptoms were perceived to be severe vs. non-severe (76.9% vs. 63.3% for itching; 76.3% vs. 66.9% for flaking/scales; $p < 0.05$). However, itching and flaking/scales were not significantly different across the % BSA-based severity grades (for mild/moderate/severe: itching, 66.6%/72.7%/68.8%; flaking/scales, 68.5%/77.5%/76.9%). Most symptoms were significantly more commonly reported by respondents with more severe symptoms using both measures of severity; however, plaques were only significantly related to the % BSA. The most notable differences were in pain and bleeding symptoms, which occurred at least 3

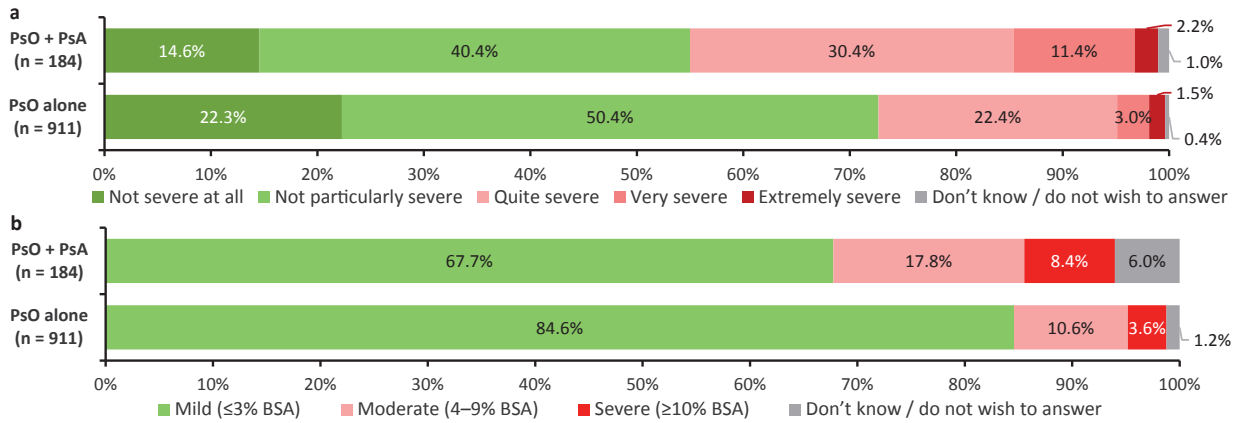

Fig. 2. Severity measures for psoriasis (PsO) symptoms, split by respondents reporting PsO and psoriatic arthritis (PsA) vs. PsO alone. (a) Respondent reported perception of severity of PsO symptoms. All categories except "extremely severe" are significantly different between PsO alone and PsO + PsA groups (Bonferroni corrected z-test, total α=0.05). (b) Estimated clinical severity based on the patient reported percentage of body surface area (% BSA) affected, which was derived from the reported sum of palm-sized areas of PsO. All categories are significantly different between PsO alone and PsO + PsA groups (Bonferroni corrected z-test, total α=0.05).

Table II. Distribution of respondent reported perception of severity of psoriasis symptoms for each estimated clinical severity category

Estimated percentage of BSA based measure of severity	Patient's perception of psoriasis severity, %				
	Not severe at all	Not particularly severe	Quite severe	Very severe	Extremely severe
Mild (≤ 3% BSA, *n* = 895)	24.7	54.4	18.2	2.0	0.6
Moderate (4–9% BSA, *n* = 129)	3.7	26.7	49.9	14.7	5.0
Severe (≥ 10% BSA, *n* = 48)	1.9	11.1	56.4	22.8	7.8

The estimates of clinical severity were based on estimates of the percentage of body surface area (% BSA) affected, which was derived from the respondent reported sum of palm-sized areas of psoriasis (n=1,072).
The Spearman's rank correlation between the 2 methods of severity measurement was 0.42.

times more often in respondents whose symptoms were severe vs. non-severe (46.9% vs. 12.1% for pain; 34.1% vs. 9.2% for bleeding; $p < 0.05$). A similar relationship was found for the % BSA-based severity measures: both pain and bleeding occurred at least 3 times more often in respondents with severe vs. mild symptoms (54.3% vs. 18.1% for pain; 51.5% vs. 12.9% for bleeding; $p < 0.05$).

Psoriatic arthritis

Severity. Most respondents with PsA ± PsO (58.7%) considered their condition to be "quite severe" or worse (**Fig. 4**a). A significantly ($p < 0.05$) greater proportion of respondents with PsA + PsO considered their condition to be "extremely severe" compared with those with PsA alone (Fig. 4b).

Symptoms. Among those with PsA ± PsO, current joint pain was reported by 48.5% of respondents, and 28.3% reported experiencing joint pain in the past 12 months. Current joint pain was reported by a significantly greater proportion of respondents with PsA ± PsO whose symptoms were severe vs. non-severe (61.9% vs. 31.7%; $p < 0.05$). Respondents with PsA ± PsO who indicated that they had experienced joint pain mostly reported the most bothersome sites of pain to be in their fingers/hands (57.1%) and in their knees (48.4%).

Joint pain was also reported by respondents who had not been diagnosed with PsA. Among patients who reported being diagnosed with PsO alone, 23.8% indicated that they had current joint pain and 18.1% said that they had experienced pain or soreness in their joints in the past 12 months.

DISCUSSION

The NORPAPP survey was based on 1,221 respondents from a population representative sample who reported physician-diagnosed PsO and/or PsA in Sweden, Denmark and Norway. The overall regional prevalence of self-reported PsO and/or PsA in this survey population was 9.7%, which included 5.7% physician-diagnosed cases and 4.0% self-diagnosed only. For physician-diagnosed cases, the prevalence of PsO was 5.1% and that of PsA was 1.5% (0.9% reported both).

Table III. Location of symptoms for respondents reporting psoriasis (PsO) alone or combined with psoriatic arthritis (PsA)

Location, %	Total (*n* = 1,095)	PsO alone (*n* = 911)	PsA + PsO (*n* = 184)
Scalp	54.9	53.4	62.2
Elbow	40.4	39.0	47.0
Other body location	27.1	26.7	29.2
Ears	24.0	21.9*	34.2*
Knees	23.0	21.4	30.6
Nails	18.6	16.0*	31.1*
Fingers	15.7	14.2	23.0
Palm of hands or sole of feet	14.9	14.1	18.7
Ankles	14.3	13.2	19.8
Back/spine	14.2	13.6	17.4
Genitals	11.7	9.4*	23.1*
Chest	11.4	10.5	16.0
Wrist	10.2	9.2	15.3
Hips	9.5	9.4	9.9
Toes	9.3	8.1	15.1
In skin folds (inverse psoriasis)	8.6	7.0*	16.4*
Arm pit	8.4	8.1	9.9
The bend of the arm	8.3	8.3	8.7
Heels	8.3	7.8	10.8
Shoulders	7.1	6.7	9.0
Neck	5.1	4.0*	10.2*
I have not experienced any symptoms in the past 12 months	2.6	3.0	0.7
Do not know/do not wish to answer	0.9	0.7	1.8

*Significant difference between PsO and PsA + PsO groups (Bonferroni corrected χ_2 test, total α=0.05).

Table IV. Location of symptoms for respondents reporting psoriasis in relation to severity

Location	Total (*n* = 1,089) %	"Not particularly severe" or better (*n* = 763) %	"Quite severe" or worse (*n* = 326) %
Scalp	55.0	52.3	61.5
Elbow	40.6	34.8*	54.1*
Other body location	27.2	23.7*	35.5*
Ears	24.1	18.2*	37.8*
Knees	23.1	17.3*	36.6*
Nails	18.7	12.9*	32.2*
Fingers	15.7	11.7*	25.1*
Palm of hands or sole of feet	15.0	12.0*	22.0*
Ankles	14.4	10.9*	22.5*
Back/spine	14.2	7.9*	28.9*
Genitals	11.7	9.1*	17.9*
Chest	11.4	6.9*	22.0*
Wrist	10.3	7.0*	17.8*
Hips	9.5	4.8*	20.6*
Toes	9.3	5.1*	19.3*
In skin folds (inverse psoriasis)	8.6	6.1*	14.5*
Arm pit	8.4	3.8*	19.1*
The bend of the arm	8.4	5.7*	14.6*
Heels	8.4	5.5*	15.0*
Shoulders	7.1	3.1*	16.6*
Neck	5.1	2.6*	11.0*
I have not experienced any symptoms in the past 12 months	2.7	3.8*	0.0*
Do not know/do not wish to answer	0.5	0.5	0.4

*Significant difference between severity groups (Bonferroni corrected χ_2 test, total α=0.05).

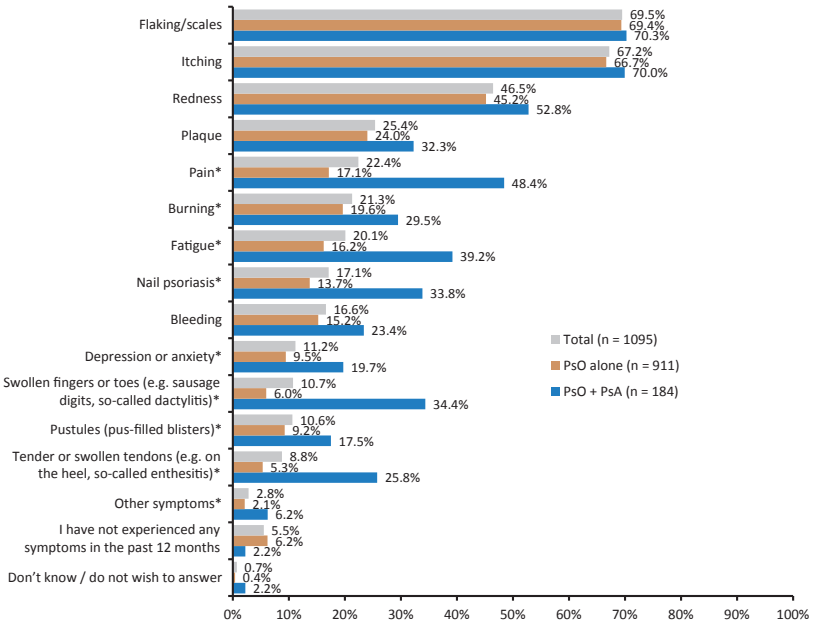

Fig. 3. Distribution of symptoms due to psoriasis (PsO, on skin, nails or scalp) experienced within the prior 12 months by all respondents reporting PsO (total), those reporting PsO alone, and those reporting both PsO and psoriatic arthritis (PsA). *Significant difference between PsO alone and PsO + PsA groups (Bonferroni corrected χ^2 test, total α=0.05).

This study was based entirely on self-reported data, including self-reporting of a physician's diagnosis and self-reporting of clinical symptoms such as affected % BSA. The NORPAPP survey results were subject to the limitations inherent to this type of respondent survey. Responses rely on the respondent's recall of facts and interpretation of the questions; because the survey was carried out online, there was no scope for questions and clarification. While the active sampling and weighting of the data was carried out to ensure that the sample population was truly representative of the populations of each country, the use of respondents registered with YouGov may have introduced some bias. These individuals have proactively registered to take part in surveys and, although this leads to very high response rates (>95% for all questions), they may not be entirely representative of the broader population. This is perhaps illustrated by the relatively high proportion of members of patient organizations (21.0% of respondents). A strength of the study is the large number of respondents from across the region, which also allows for comparison between individual countries. Pooling of data from the Scandinavian countries included in this report was justified because of the very similar healthcare systems and access to treatments across all 3 countries (18).

PsO prevalence data reported in the literature varies widely and comparison across studies, even within geographical regions, can be complicated by differences in the type of study population, the method of assessment and the time-frame assessed. A systematic review of studies published up to November 2015 (3) found the lowest prevalence (0.51–1.13%) reported in the USA, based on Medicare claims made in 2011 (19), and the highest prevalence (11.4%) reported in North Norway, based on self-reported lifetime prevalence in a population survey carried out in 2007 to 2008 (the sixth Tromsø study) (10). Although the total self-reported prevalence in the current study was consistent with the overall self-reported prevalence in the sixth Tromsø study, these levels of prevalence seem to be generally higher than the self-reported

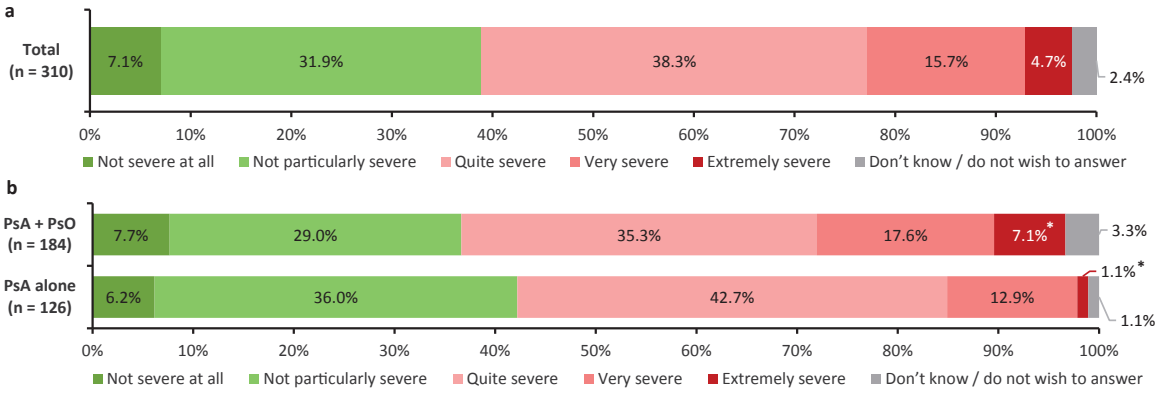

Fig. 4. Respondent reported perception of severity of psoriatic arthritis (PsA) symptoms for: (a) all respondents reporting PsA (total); and (b) split by patients reporting PsA alone and those reporting both PsA and PsO. *Significantly different (Bonferroni corrected z-test, total α=0.05).

prevalence from other reports, for example, a prevalence of 3.9% was reported in a 2004 to 2005 nationwide skin-disease survey in Sweden (6) and 5.8% was reported in the third survey of the Nord-Trøndelag Health Study in Norway (HUNT3, 2006–2008) (4). Notably, in our initial survey population, self-diagnosed individuals made up 40% of the total respondents who stated that they had PsO and/or PsA. In the sixth Tromsø study, the self-reported prevalence of physician-diagnosed PsO was 9.9% and the total self-reported prevalence of PsO was 11.4%, so, of the respondents reporting that they had PsO, 13% were self-diagnosed only (10). Conversely, the HUNT3 study, a validation exercise in which a representative subset of respondents took part in a clinical interview and extensive skin examination using strict definition criteria, revealed a higher prevalence of PsO than the self-reported prevalence (8.0% vs. 5.8%) (4). However, among the 16 "false-negative" respondents who were diagnosed with PsO in the validation examination, 12 had mild scalp PsO only. Exclusion of these respondents reduced the prevalence of PsO in the validation study to 5.2%. Also, notably in our study, the proportion of respondents who were self-diagnosed was lower in the older age group (45–74 years; 33%) than in the younger age group (18–44 years; 48%). This may be a result of increased secondary diagnosis among older respondents who are more likely to visit a physician for other health issues or it may reflect a longer duration of disease in the older group, providing more time to seek and obtain a diagnosis. It is also possible that younger respondents were more likely to have self-diagnosed based on information from the Internet. For most respondents who specified the timing of their diagnosis, there was a delay of at least one year between the onset of symptoms and diagnosis by a physician. The delay in diagnosing PsA alone was greater than the delay in diagnosing PsO alone, which might be expected given the potential range of causes for the symptoms of PsA. Perhaps less expected was that the increased delay in PsA diagnosis was also evident in the population of respondents with PsA + PsO, since most would have had PsO first (11, 20). This is consistent with the findings of the PREPARE study, which found that almost a third of patients (30.0%) with PsO seen in 34 dermatology centres in Europe and North America had PsA as determined by rheumatologists, and more a third (41.1%) of these patients with PsA had not previously been given the diagnosis (21). These observations are also consistent with the fact that of the patients in our survey who reported a diagnosis of PsO only, 23.8% indicated that they were currently experiencing joint pain. It is possible that some of these patients may have been suffering from undiagnosed PsA.

The reported diagnosis of 126 respondents with PsA, but not PsO, representing 40.6% of all respondents with PsA, seems high. While PsA can occur in people without skin PsO (22), particularly in those with relatives with PsO, the proportion of respondents with PsA who initially develop joint symptoms in the absence of any identified signs of PsO is generally reported to be 15–30% (11). In the MAPP survey, 21% of respondents with PsA reported that they had experienced joint symptoms before they experienced any skin symptoms (23). There could be several reasons for the higher proportion of respondents with PsA, but not PsO in this survey; for example, the psoriatic component of the diagnosis could be based on family history, while there was no active PsO at the time of diagnosis or the time of the survey, or the respondent may have been seen first by a rheumatologist who did not flag the PsO as a specific separate diagnosis. A limitation of our survey is that data were not collected about the relative timing of diagnosis of PsO and PsA in respondents reporting both conditions.

Comparing self-assessed severity with the patient estimated % BSA-based clinical severity of PsO symptoms confirmed that the clinical measure is of limited value in capturing respondent perceptions: within each category of clinical severity there was a substantial spread of respondent perceived severity. Self-assessed severity was significantly related to symptoms of itching and flaking/scales, whereas % BSA-based clinical severity was not. For symptoms of PsO, both the respondents' perception and clinical severity were significantly worse for respondents who also had PsA. Overall, respondents perceived PsA symptoms to be more severe than those of PsO. In general, respondents' perception of the severity of PsA symptoms followed a similar pattern, whether or not they also had PsO. However, among the small group of respondents who described their PsA symptoms as "extremely severe", a significantly ($p<0.05$) higher proportion had PsO + PsA compared with PsA alone. The degree of alignment between respondent perceptions of the severity of PsO and % BSA is generally in line with results from the MAPP survey, which showed that while dermatologists judged severity primarily on the size and location of lesions, patients judged severity by a broader range of factors, led by itching (24). In the MAPP survey, respondents were asked to rate the severity of their disease at its worst on a 1–10 scale from "very mild" to "very severe", which was then recorded into a 3-level measure (mild, moderate, severe): 27% of respondents with PsO rated their disease as "severe" (defined as 8–10 on the scale), whereas the majority of respondents with PsA (53% of the subset who had joint pain) rated their disease as "severe" (23). Although this scale does not map onto the NORPAPP data perfectly, as both the divisions and language are different, the findings are compatible: 27% of the NORPAPP PsO alone group rated their symptoms "quite severe" or worse, as did 59% of the PsA ± PsO group.

In conclusion, the results of this survey indicate that there is a high burden of PsO and PsA in all 3 of the Scandinavian countries included in this study. Patients'

perceptions of the severity of their condition did not correlate well with clinical severity, which suggests that new approaches to the assessment and management of PsO may be beneficial.

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