Psoriasis: Targets and Therapy

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ORIGINAL RESEARCH

Prevalence of Genital Psoriasis and Its Impact on Patients' Sexual Life in Routine Care: Epidemiologic Survey in Germany

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Purpose: Psoriatic disease (PsO) involving the genital region (GenPsO) or areas of sexual interest (ASI; anal region, gluteal area, groin, lower back, and chest/breast) is associated with impaired quality of life (QoL), sexual burden, and avoidance of sexual life. This nested cohort study investigated the prevalence and effect of GenPsO and PsO at any ASI in routine German care.

Methods: Adult patients enrolled in the PsoBest registry were surveyed by mail. Main endpoints were prevalences of GenPsO and PsO at any ASI in the past 12 and 24 months. The reasons for sexual impairment (RSI) questionnaire, the Genital Psoriasis Symptoms Scale (GPSS), the Genital Psoriasis Sexual Impact Scale, demographics, and disease characteristics were assessed.

Results: Questionnaires were returned by 811/2010 (40.3%) patients; 795 (39.6%) complete sets were analyzed. Mean (SD) age at onset was 35.0 (14.0) years for GenPsO, and 34.1 (14.9) years for PsO at any ASI. Period prevalence was 21.6% (n=172) for GenPsO and 49.2% (n=391), for PsO at any ASI in the last 24 months, and 10.8% (n=86) and 26.7% (n=212), respectively, at day of survey. Systemic therapy was used by 84.9% (n=73) of patients with GenPsO and 83.0% (n=176) with PsO at any ASI. Mean (SD) GPSS sum score was 27.6 (18.6). In the past 30 days, 60.5% (n=52) of patients with GenPsO and 35.4% (n=75) with PsO at any ASI experienced sexual impairment. Among patients with GenPsO, 40.7% (n=35) reported always avoiding sexual activities during the past week. RSI included stress, lack of self-confidence, and PsO-related pain/movement restrictions.

Conclusion: Given the high prevalence of GenPsO and its extensive effect on patient QoL and sexual well-being, it is essential that genital and ASI regions are examined at each routine clinical appointment and that appropriate treatment is offered to minimize negative consequences and cumulative life course impairment.

Keywords: psoriasis in areas of sexual interest, psoriatic disease, psychosocial burden, sexual impairment

Introduction

Psoriatic disease (PsO) is a chronic, inflammatory condition characterized by erythematous plaques that can affect any area of the skin, including the genitals and other areas of sexual interest (ASI), such as the anal region, gluteal area, groin, lower back, and chest/breast.[1] Onset of genital PsO (GenPsO) usually follows several years after the first signs of PsO and is often recurring.[2] The reported prevalence of GenPsO or PsO at other ASI among patients with PsO varies widely (14%–64%).[3–12] An analysis in 2019 of large-scale routine data from German dermatologists revealed that 17%, 24%, 25%, and 41% of patients had genital, groin, anal, or gluteal region PsO, respectively.[6]

GenPsO and PsO at any ASI are associated with declines in quality of life (QoL) avoidance of sexual contacts, and occurrence of sexual dysfunction, leading to increased disease burden.[4,5,8,13,14] Routine discussions about GenPsO and examinations of the genital area during healthcare visits for patients with PsO are needed to enable appropriate diagnosis and treatment of GenPsO.[4,14,15]

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According to current European and German treatment guidelines, PsO should be classified as moderate to severe if genital involvement is present. Because of the serious effect it has on patients' lives, GenPsO qualifies for systemic therapy even if PsO disease severity criteria for systemic therapy (affected body surface area [BSA] >10 or Psoriasis Area and Severity Index [PASI] >10, and Dermatology Life Quality Index [DLQI] >10) are not otherwise met.[16–18] As even minimal GenPsO can have a major impact on patients' lives, treatment is an important step toward avoiding or lessening its effect on QoL and sexual well-being.[19] Unfortunately, because of the shame and stigma associated with GenPsO and PsO at any ASI, these conditions and their effect on a patient's sex life and QoL are not routinely discussed by patients and their healthcare providers, and examinations of patients with PsO frequently do not include the genital region.[7,20] If left ignored and untreated, the cumulative effect of stigma and psychological and physical comorbidities among patients with GenPsO may lead to negative life consequences and cumulative life course impairment (CLCI).[21,22] The objective of this nested cohort study on GenPsO was to investigate its prevalence and its effect on sexual life in patients with PsO from the national German PsO registry, PsoBest.[23]

Methods

Study Design

GPS-Best[24] is a cross-sectional patient survey within a nested cohort study of adult patients participating in PsoBest.[23] The study consisted of two parts. In part A, the current and period prevalence of GenPsO (genital area, such as penis, vulva, and area up to the anus) and PsO at any ASI (GenPsO, anal and gluteal area, groin, lower back, or chest/breast) and the level of sexual impairment was assessed using a cross-sectional epidemiological survey. Part B is an ongoing, prospective, observational, non-interventional study to assess the effectiveness of risankizumab therapy on GenPsO and the effect of treatment on sexual impairment in a real-life setting. The study was approved by the ethics committee of the University Medical Center Hamburg-Eppendorf (UKE) in Hamburg, Germany (number LPEK-0244). Informed consent was obtained from all patients involved in the study. Results from part A are reported here. Questionnaires were sent by mail in an anonymous form to a consecutive, non-selected sample of patients in the PsoBest registry. The investigators had no access to identifiable patient data at any point during the data analysis.

The PsoBest registry received an ethics votum No. 2805 of the ethics committee of the Medical Association of Hamburg on 24 July 2007, last amendment 8 October 2024, and confirmed that there was no further ethical approval necessary for the retrospective analysis of the anonymized data in accordance with the ethical standards of the responsible committees (institutional or regional) and with the Helsinki Declaration in its current version.

Outcome Measures

All participants completed a questionnaire on areas affected by PsO and participants with GenPsO, PsO at any ASI, or nail PsO were asked to complete additional questionnaires on sexual health. The primary study endpoints were period prevalences of GenPsO and PsO at any ASI in the past 12 and 24 months.

Secondary endpoints included point prevalence of GenPsO or PsO at any ASI at the day of questionnaire completion, prevalence of sexual impairment, exploratory analysis of the reasons for sexual impairment (RSI questionnaire), mean severity of GenPsO symptoms (assessed by the Genital Psoriasis Symptom Scale [GPSS]),[25] proportion of patients avoiding sexual activity or noticing a change in their sexual activity due to GenPsO (assessed by the Genital Psoriasis Sexual Impact Scale [GPSIS][19] and the RSI questionnaire), and proportion of patients satisfied with the efficiency of their current therapy in controlling GenPsO symptoms.

The GPSS[25] includes 8 questions pertaining to GenPsO symptoms, with possible responses ranging from 0 (no symptoms) to 10 (worst symptom imaginable); when all items are answered, the GPSS sum score is calculated (range, 0–80).[25] The GPSIS[19] assesses the level of avoidance of and impact on sexual activity due to GenPsO and includes 3 questions that build 2 subscales: the avoidance subscale and impact subscale. In the avoidance subscale, patients report whether they were sexually active in the past week; if no, they reported whether they avoided sexual activity because of GenPsO or, if yes, they reported how often GenPsO symptoms interfered with sexual activity (ranging from 1 [never] to 5 [always]). In the impact subscale, patients who reported sexual activity during the past week were asked about the level

of worsening of GenPsO symptoms during or following sexual activity (1 [very low/not at all] to 5 [very high]).[19] The RSI questionnaire, which was developed by investigators for the purpose of this study, includes a list of 13 generic and 7 PsO-specific reasons why sexual impairment might occur, which are rated on a scale of 0 (no influence) to 5 (highest possible influence).

Statistical Analyses

Descriptive statistics, including absolute and relative frequencies, mean, and standard deviation (SD) are reported. Prevalence is reported as total number and percentage of patients with GenPsO or ASI involvement. For the sum score analysis of GPSS in patients with GenPsO, the proportions of patients with sum scores <20, 20–40, and >40 are reported. For comparison of the RSI questionnaire results, three patient groups were identified based on areas of PsO involvement: patients with GenPsO, patients with PsO at any ASI, and patients with nail PsO (55% with ASI involvement, 45% without) as a control for the effect of PsO location. The frequency of each RSI in patients with GenPsO or PsO at any ASI was compared with the frequency in patients without the respective PsO involvement using chi-square tests. Data analyses were performed using SPSS version 27 for Windows (IBM® SPSS® Statistics for Windows; Armonk, NY, USA).

Results

Patient Demographics

Of the 2010 questionnaires sent, 811 (40.3%) were returned, of which 795 (39.6%) were completed and were included in the analysis. Among these patients, 41.9% were female, 51.6% were male, and 6.5% did not report their gender (Table 1). Mean (SD) age at the time of completing the questionnaire was 54.5 (13.6) years, and mean (SD) age at GenPsO onset was 35.0 (14.0) years, following the onset of PsO by approximately 8 years. Among patients with GenPsO and PsO at any ASI, 84.9% and 83.0%, respectively, were currently receiving systemic therapy (Table 2). Mean (SD) duration of systemic treatment was 2.8 (4.6) years for patients with GenPsO and 2.8 (2.9) years for patients with PsO at any ASI.

Table 1 Baseline Demographics, Clinical Characteristics, and Current Treatment of Patients with GenPsO or PsO at Any ASI

	Current GenPsO (n=86)	Current PsO at Any ASI (n=212)	Total Population (N=795)
Demographic characteristics			
Age, mean (SD), y	50.5 (12.2) n=83	53.2 (13.6) n=200	54.5 (13.6) n=741
Female sex, n (%)	38 (44.2)	88 (41.5)	333 (41.9)
Weight, mean (SD), kg	91.8 (24.1) n=83	91.5 (23.2) n=199	89.9 (21.3) n=738
Clinical characteristics, mean (SD)			
Age at PsO onset, y[a]	27.4 (13.9) n=77	27.0 (15.4) n=178	26.6 (14.9) n=249
Age at GenPsO onset, y[a]	35.2 (13.1) n=73	34.8 (13.8) n=110	35.0 (14.0) n=141
Age at PsO at any ASI onset, y[a]	32.4 (12.6) n=75	34.4 (15.39) n=166	34.1 (14.9) n=211
Duration of PsO, y	22.3 (12.8) n=80	25.3 (14.5) n=190	26.4 (14.5) n=269
Current treatment, n (%)[b]			
Systemic	73 (84.9)	176 (83.0)	—
Topical (not systemic)	11 (12.8)	24 (11.3)	—
Other[c]	1 (1.2)	2 (0.9)	—
None	1 (1.2)	10 (4.7)	—

Notes: [a]Age at onset was calculated using year of birth (derived from age at questionnaire completion subtracted from year of completion [2021]) and stated year of first appearance.[b]Treatment data were available only for patients with PsO at any ASI and/or GenPsO.[c]PsO treatment that was neither systemic nor topical.

Abbreviations: ASI, area of sexual interest; GenPsO, genital psoriasis; PsO, psoriasis.

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Table 2 Prevalence of GenPsO and PsO at Any ASI on the Day of Questionnaire Completion and in the Past 12 and 24 Months

	Patients, n (%) (N=795)	
	GenPsO	**PsO at Any ASI**
Day of questionnaire completion	86 (10.8)	212 (26.7)
Past 12 mo	129 (16.2)	314 (39.5)
Past 24 mo	172 (21.6)	391 (49.2)
Ever	354 (44.5)	640 (80.5)

Abbreviations: ASI, area of sexual interest; GenPsO, genital psoriasis; PsO, psoriasis.

Prevalence of GenPsO and PsO at Any ASI

Prevalence of GenPsO and PsO at any ASI at the time of questionnaire completion was 10.8% (n=86) and 26.7% (n=212), respectively. Period prevalence of GenPsO and PsO at any ASI in the past 12 months was 16.2% (n=129) and 39.5% (n=314), respectively, and in the past 24 months was 21.6% (n=172) and 49.2% (n=391), with a lifetime prevalence of 44.5% (n=354) and 80.5% (n=640) (Table 2).

Symptoms and Sexual Impairment

Among patients with GenPsO at the time of questionnaire completion (n=86), mean scores for GPSS items ranged from 2.0 to 4.7, with redness, itching, and discomfort having the highest mean scores (Figure 1A). The mean (SD) GPSS sum score was 27.6 (18.6) out of 80 (<20, 39.5%; 20–40, 34.9%; >40, 19.8%; Figure 1B). When analyzed by treatment, mean GPSS sum score was 27.5 (median, 23.0) among users of systemic therapy (n=69) and 29.7 (median, 24.0) among users of topical therapy (n=11).

Based on responses to the avoidance subscale of the GPSIS, 40.7% (n=35) of patients reported always avoiding sexual activities within the past week (Figure 1C): 12.8% (n=11) due to GenPsO and 27.9% (n=24) due to factors other than GenPsO. An additional 20.9% (n=18) of patients reported sometimes or often avoiding sexual activities within the past week because of GenPsO. Among patients with GenPsO who had experienced sexual activity during the past week (n=45), change in GenPsO symptoms as scored on the GPSIS was none or very low for 28.9% (n=13), low for 0.0%, medium for 60.0% (n=27), high for 11.1% (n=5), and very high for 0.0% of patients.

At the time of questionnaire completion, 50.0% (43/86) and 60.5% (52/86) of patients with GenPsO reported an impaired sex life (when considering all sexual activities) during the past 7 and 30 days, respectively, compared with 28.8% (61/212) and 35.4% (75/212) of patients with PsO at any ASI (Figure 2).

Among the 13 generic RSIs, 4 were considered relevant significantly more often among patients with versus without GenPsO (lack of self-confidence, P=0.019; altered hormone status, P=0.027; loss of libido, P=0.009; relationship conflicts, P=0.006) and 5 were relevant significantly more often among patients with versus without PsO at any ASI (stress in general, P=0.004; lack of self-confidence, P=0.010; other disease, P=0.048; consequences of experienced abuse, P=0.035; relationship conflicts, P=0.010; Table 3).

Among the 7 PsO-specific RSIs, all but 1 (orgasm disorder) were significantly more relevant among patients with versus without GenPsO, and all 7 were significantly more relevant among patients with versus without PsO at any ASI (Table 3).

The most common PsO-specific RSI for patients with GenPsO and those with PsO at any ASI were pain during sexual stimulation (55.0% and 33.7%, respectively), movement restrictions/painful skin (47.6% and 37.4%), and loss of libido (45.0% and 33.3%).

Among patients with PsO but without GenPsO or involvement of ASI, prevalence of pain during sexual stimulation was reported by 6.7%, movement restrictions/painful skin by 14.7%, and loss of libido by 20.0%, whereas patients with nail PsO (55% with and 45% without ASI involvement) reported prevalence of 22.7% for pain during sexual stimulation, 28.6% for movement restrictions/painful skin, and 25.9% for loss of libido; Table 4).

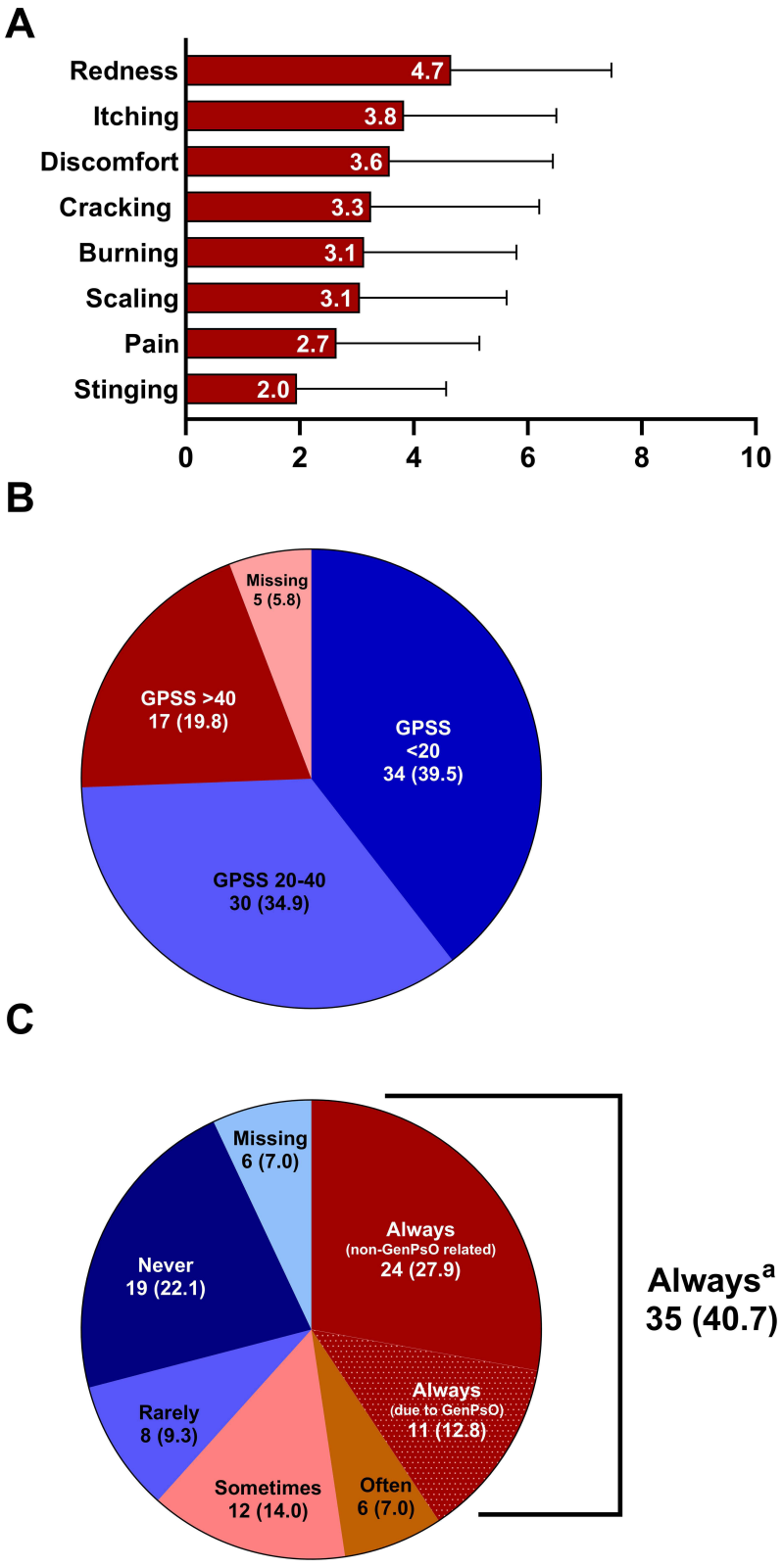

Figure 1 (**A**) Mean scores on GPSS items, (**B**) GPSS Sum Scores, and (**C**) proportion of patients avoiding sexual activities within the past week in patients with GenPsO (n=86). Data reported as mean in (**A**) and n (%) in (**B**) and (**C**). In (**A**) severity of each symptom was rated from 0 (no symptoms) to 10 (worst symptom imaginable). Avoidance of sexual activities is based on GPSIS avoidance subscale. [a]Always includes always due to GenPsO (n=11) and always due to other non-GenPsO–related reasons (n=24).

Abbreviationa: GPSS, Genital Psoriasis Symptom Scale; GPSIS, Genital Psoriasis Sexual Impact Scale; GenPsO, genital psoriasis.

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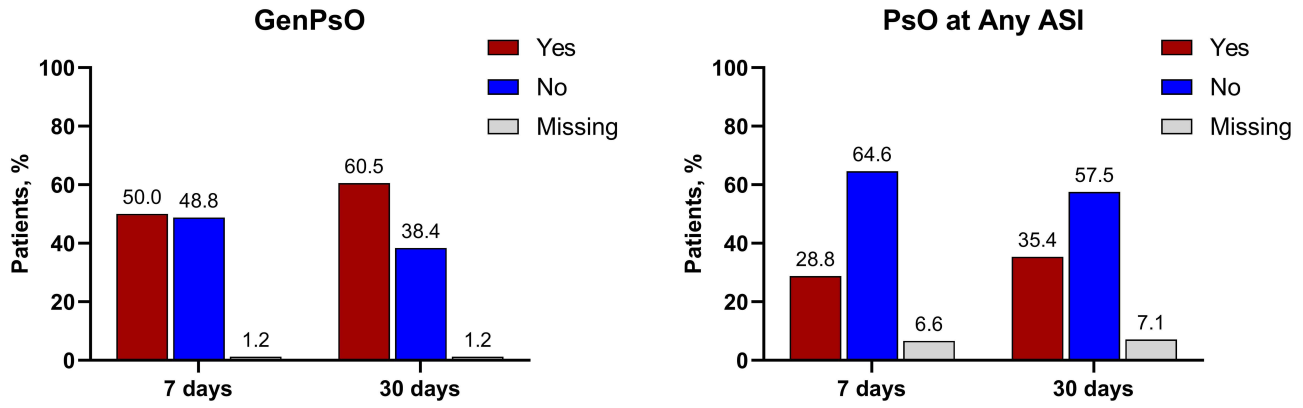

Figure 2 Proportion of patients with impaired sex life within the past 7 days and 30 days in patients with GenPsO (n=86) and PsO at any ASI (n=212) based on questions on sexual impairment.
Abbreviations: ASI, area of sexual interest; GenPsO, genital psoriasis; PsO, psoriasis.

Discussion

In this cross-sectional, patient-reported, epidemiologic survey on the prevalence of GenPsO and its effect on patients' sexual life among patients from the PsoBest registry in Germany, almost 50% of patients had experienced GenPsO and 81% had experienced PsO at any ASI at some time in their lives. The lifetime prevalence of GenPsO is remarkably high, given the rather low point prevalence of 10.8% in the current study and is comparable with the 16.5% reported by a previous large scale German study.[6] Median time between onset of PsO and GenPsO was approximately 8 years (age at onset of GenPsO ranged from 1 to 69 years), which is consistent with a previous Dutch study that reported a median time of 8 years for GenPsO onset after PsO diagnosis.[2] Given the high lifetime prevalence of GenPsO and PsO at any ASI, dermatologists should routinely examine these areas. Furthermore, PsO that starts at any ASI may progress to genital areas, suggesting that early treatment adjustments may help to avoid GenPsO in these patients.

Our findings demonstrate that GenPsO can have a serious negative effect on patients' sexual activity, with most patients reporting sexual impairment in the last 30 days. Avoidance of sexual activity was also common, with 1 in 8 patients with GenPsO always avoiding sexual activity specifically because of their condition. As a primary objective, the RSI in patients with such disturbances were assessed. A high disease burden was reported, some of which were psychosocial in nature (eg, stress, loss of libido, and lack of self-confidence) and some directly related to psoriatic lesions (eg, pain, movement restrictions), confirming the broad spectrum of factors contributing to the overall negative effect of PsO on sexual life. These results are consistent with previous studies that have demonstrated the high burden that GenPsO places on patients' lives, including on their sexual activity and QoL.[4,8,11,26] A Polish study (n=109) demonstrated significant sexual problems and significant impairment in QoL in patients with GenPsO,[8] and a German study (n=344) reported that significantly more patients with GenPsO than without avoided sexual activity (74.2% vs 52.7%; $P<0.001$) and were dissatisfied with their sex life due to PsO (73.2% vs 57.5%; $P<0.001$), citing shame, pain, and fear of rejection as the main reasons for avoiding sexual activity.[26] Another German study reported that patients with anogenital PsO experienced more impairment in QoL and sexual functioning than patients with PsO without anogenital involvement despite their current treatment with conventional systemic therapy (53.1%), biological therapy (13.5%), and topical therapy (96.1%).[4] Although most cases of PsO are generally mild and manageable with topical therapy,[27,28] patients with moderate to severe PsO or GenPsO qualify for systemic treatment.[17,29] In PsoBest, 84.9% and 83.0% of patients with GenPsO and PsO at any ASI, respectively, were receiving treatment with systemic therapy, yet 54.7% had a GPSS sum score of >20 (20–40, 34.9%; >40, 19.8%), indicating still active lesions in spite of systemic treatments in many patients. However, given the cross-sectional nature of the current study, it is not possible to characterize the long-term effects of systemic treatment with these data.

The European consensus on treatment goals in psoriasis strongly recommends the use of systemic treatments in "upgrade" PsO situations, including with genital and anal involvement, even in the absence of further body lesions.[18]

Table 3 Reasons for Sexual Impairment Among Patients with/without GenPsO and with/without PsO at Any ASI

	Influence,[a] n (%)					
	Patients with GenPsO (n=83)[b]	**Patients without GenPsO (n=194)[b]**	**Chi² test *P***	**Patients with PsO at Any ASI (n=199)**	**Patients without PsO at Any ASI[c] (n=78)**	**Chi² test *P***
Generic						
Alcohol or drugs	2 (2.4)	15 (7.9)	0.086	11 (5.6)	6 (7.7)	0.520
Medication	8 (9.6)	14 (7.3)	0.502	18 (9.1)	4 (5.1)	0.274
Stress in general	45 (54.2)	82 (42.3)	0.067	**102 (51.3)**	**25 (32.1)**	**0.004**
Religious belief	0 (0)	3 (1.6)	0.255	2 (1.0)	1 (1.3)	0.839
Depression/depressive symptoms	25 (30.1)	45 (23.2)	0.224	56 (25.1)	14 (17.9)	0.079
Lack of self-confidence	**37 (45.1)**	**59 (30.4)**	**0.019**	**78 (39.4)**	**18 (23.1)**	**0.010**
Altered hormone status	**17 (21.0)**	**21 (10.9)**	**0.027**	28 (14.3)	10 (12.8)	0.751
Other disease	11 (13.4)	24 (12.4)	0.824	**30 (15.2)**	**5 (6.4)**	**0.048**
Erectile dysfunction/ ejaculation disorders	14 (17.1)	27 (14.2)	0.545	27 (13.9)	14 (17.9)	0.401
Libido loss	**37 (44.6)**	**55 (28.5)**	**0.009**	69 (34.8)	23 (29.5)	0.395
Consequences of experienced abuse	5 (6.0)	6 (3.2)	0.268	**11 (5.6)**	**0 (0)**	**0.035**
Relationship conflicts	**22 (26.5)**	**25 (13.0)**	**0.006**	**41 (20.7)**	**6 (7.7)**	**0.010**
Strained relationship	10 (12.2)	13 (6.8)	0.138	17 (8.7)	6 (7.7)	0.792
PsO-specific						
Pain during sexual stimulation	**44 (55.0)**	**27 (14.1)**	**<0.001**	**66 (33.7)**	**5 (6.7)**	**<0.001**
Movement restrictions/ painful skin	**39 (47.6)**	**46 (24.1)**	**<0.001**	**74 (37.4)**	**11 (14.7)**	**<0.001**
Sadness	**23 (28.0)**	**28 (14.7)**	**0.009**	**46 (23.2)**	**5 (6.7)**	**0.002**
Lack of self-confidence	**28 (34.1)**	**37 (19.6)**	**0.010**	**58 (29.6)**	**7 (9.3)**	**<0.001**
Libido loss	**36 (45.0)**	**44 (23.2)**	**<0.001**	**65 (33.3)**	**15 (20.0)**	**0.032**
Orgasm disorder	13 (16.0)	24 (12.6)	0.453	**32 (16.3)**	**5 (6.7)**	**0.038**
Relationship burdened by psoriasis	**22 (27.5)**	**20 (10.5)**	**<0.001**	**41 (21.0)**	**1 (1.3)**	**<0.001**

Note: Statistically significant differences ($P < 0.05$) shown in bold.[a]Influence ranges from a little to very much. [b]Response totals may not sum to column total due to missing responses; percentages are calculated based on the number of non-missing responses. [c]Patients with PsO, but without GenPsO and without PsO at any ASI, and without nail psoriasis, who completed additional sexual health questionnaires, although the questionnaire design did not provide for this.
Abbreviations: ASI, area of sexual interest; GenPsO, genital psoriasis; PsO, psoriasis.

Table 4 Reasons for Sexual Impairment That are Significant in Patients with GenPsO and with PsO at Any ASI vs without GenPsO/PsO at Any ASI[a] and Patients with Nail PsO

RSI, n (%)	**GenPsO (n=86)**	**PsO at Any ASI (n=212)**	**No GenPsO/PsO at Any ASI[a] (n=78)**	**Nail PsO (n=185)**
Generic				
Stress in general	**45 (54.2)**	**102 (51.3)**	25 (32.1)	81 (43.8)
Lack of self-confidence	**37 (45.1)**	**78 (39.4)**	18 (23.1)	60 (32.4)
Other disease	11 (13.4)	**30 (15.2)**	5 (6.4)	22 (11.9)
Loss of libido	**37 (44.6)**	69 (34.8)	23 (29.5)	61 (33.0)
Consequences of experienced abuse	**5 (6.0)**	**11 (5.6)**	0 (0)	8 (4.3)
Relationship conflicts	**22 (26.5)**	**41 (20.7)**	6 (7.7)	33 (17.8)
PsO-specific				
Pain during sexual stimulation	**44 (55.0)**	**66 (33.7)**	5 (6.7)	42 (22.7)
Movement restrictions/painful skin	**39 (47.6)**	**74 (37.4)**	11 (14.7)	53 (28.6)
Sadness	**23 (28.0)**	**46 (23.2)**	5 (6.7)	29 (15.7)
Lack of self-confidence	**28 (34.1)**	**58 (29.6)**	7 (9.3)	42 (22.7)

(*Continued*)

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Table 4 (Continued).

RSI, n (%)	GenPsO (n=86)	PsO at Any ASI (n=212)	No GenPsO/PsO at Any ASI[a] (n=78)	Nail PsO (n=185)
Loss of libido	**36 (45.0)**	**65 (33.3)**	15 (20.0)	48 (25.9)
Orgasm disorder	13 (16.0)	**32 (16.3)**	5 (6.7)	**26 (14.1)**
Relationship burdened by PsO	**22 (27.5)**	**41 (21.0)**	1 (1.3)	27 (14.6)

Notes: Statistically significant difference ($P < 0.05$) shown in bold: patients with no GenPsO/PsO at any ASI vs patients with GenPsO or PsO at any ASI based on chi-square test. [a]Patients with PsO but without GenPsO, and without PsO at any ASI, and without nail psoriasis, who completed additional sexual health questionnaires, although the questionnaire design did not provide for this.
Abbreviations: ASI, area of sexual interest; GenPsO, genital psoriasis; PsO, psoriasis; RSI, reasons for sexual impairment.

Thus, all patients with GenPsO should be considered candidates for systemic treatment, in particular when showing relevant disease burden. In accordance, a large majority of patients in the current study were receiving systemic treatment. High treatment response, durability, and tolerability of systemic therapies have been shown in patients with GenPsO.[19,30] However, patients with GenPsO may still experience symptoms such as itch, burning, and redness, regardless of treatment. Adequate treatment can significantly reduce symptoms,[19] and treatment switches from topical to systemic therapy or from one systemic therapy to another should be considered when current treatment is not sufficient. Early treatment of GenPsO and PsO at an ASI may mitigate symptoms and reduce the development of self-esteem issues, anxiety, and depression, thus potentially interrupting a vicious cycle of disease progression and worsening QoL.[31] By encouraging patients to discuss their GenPsO and PsO at any ASI and educating them on the possible psychosocial components of the disease, healthcare providers can take an important first step in reducing the effect of GenPsO on patients' sexual and emotional lives.

Minimal disease in the genital area still causes considerable impact. Therefore, therapies with high treatment response (100% improvement in PASI or low absolute PASI) over time are necessary to treat symptoms of disease as well as improve QoL. Furthermore, high treatment response (PASI 100) and improvements in QoL have been shown to lower economic costs and increase social benefits in patients with PsO.[32]

Because of the chronic nature of PsO, patients with PsO and GenPsO usually experience disease symptoms and recurrence for long periods of time. In this study, the proportion of patients who reported ever having GenPsO was 4-fold greater than the proportion of those experiencing GenPsO on the day of the questionnaire. Although our findings, together with previous studies, show the considerable impact of GenPsO on sexual health and well-being, there are currently no reports on GenPsO and its association with CLCI. However, the negative effect of GenPsO on patients' lives could lead to lifelong negative consequences and CLCI.[21,22] Future studies are needed to assess this, and the first measurement tools to assess CLCI in patients with chronic skin diseases were recently developed.[33]

From the clinical point of view, it is remarkable that affectation of the nails interferes with sexual activity and leads to sexual impairment. Again, this sheds a light on the need to stringently treat psoriatic areas of limited size but great psychosocial and functional importance.

Until recently, there had been no consensus specifically on the treatment or management of genital psoriasis within the published international guidelines.[34] Consensus recommendations outlined by the Genital Psoriasis Wellness Consortium highlights the need for a multidisciplinary patient-centered approach to genital psoriatic disease, based on diagnosis of and communication about GenPsO with the patient including assessing the effects on patients' QoL and relationships and hence optimal treatment choice.[34] With sexual function a patient-sensitive topic, such a multidisciplinary model may help provide a more comprehensive and holistic approach to management of genital psoriasis.

Limitations of this study include potential bias of patient-reported data. The data were collected in a cross-sectional survey via a questionnaire for which patients had to recall disease history over a prolonged period (past 12–24 months and lifetime). The 40% response rate, although considered a positive response rate, may itself have been subject to bias. Patients may have not responded to the questionnaire because of shame/embarrassment or

because they had not been affected by GenPsO. Both of these factors might negatively affect interpretation of these results, but at the same time, these motives for nonresponse may cancel each other out. Current treatments were based on patient information, and the specific treatment the patient was taking was not always identifiable. Other limitations include unknown disease activity and severity at time of questionnaire completion, the self-developed (for this study) and non-validated RSI questionnaire, and lack of a control group without PsO. Questionnaires were returned anonymously by mail, and therefore attribution to data from the PsoBest database is not possible. Additionally, detailed patient data were not recorded for certain comorbidities, particularly psoriatic arthritis, which can be a key factor in sexual function. Strengths of the study include the large patient cohort (providing high external validity for moderate to severe psoriasis in Germany). Moreover, the identification of RSI is a de novo approach that has not been applied in such a large-scale cohort previously. Additional strengths include two investigational subgroups (GenPsO and PsO at any ASI) with two respective reference groups (patients with nail PsO but without GenPsO and without PsO at any ASI).

Conclusions

To our knowledge, this is one of the first studies investigating RSI among patients with GenPsO or PsO at any ASI. Overall, the prevalence of GenPsO and PsO at any ASI was substantial among patients in the PsoBest registry, and the impact of GenPsO and PsO at any ASI on sexual activity and well-being was considerable. These results suggest that dermatologists should include examination of patients' genital areas for PsO, adjust treatment if needed, and discuss GenPsO and sexual impairment with patients to help avoid stigmatization and CLCI.

Abbreviation

ASI, areas of sexual interest; BSA, body surface area, CLCI, cumulative life course impairment; DLQI, Dermatology Life Quality Index; GenPsO, psoriatic disease involving the genital region; GPSIS, Genital Psoriasis Sexual Impact Scale; GPSS, Genital Psoriasis Symptoms Scale; PASI, Psoriasis Area and Severity Index; PsO, Psoriatic disease; QoL, Quality of life; RSI, Reasons for sexual impairments.

Data Sharing Statement

Data are not publicly available. There are restrictive registry rules for access. Moreover, European legislation as well as informed consent given prohibits the sharing of medical and health data from the registry for privacy issues. An anonymization of detailed medical and health records is not possible.

Ethics Approval and Informed Consent

PsoBest registry received an ethics votum No. 2805 of the ethics committee of the Medical Association of Hamburg on 24 July 2007, last amendment 21 October 2024. To conduct and analyze the anonymized questionnaire survey of a subpopulation of PsoBest (GPS-Best part A, as described here), an approval from the ethics committee of the University Medical Center Hamburg-Eppendorf (UKE) in Hamburg, Germany (number LPEK-0244) was received. In addition, the PsoBest nested cohort study GPS-Best part B received an ethics votum No. 2021-10592 of the ethics committee of the Medical Association of Hamburg on 05 August 2021. We confirm that informed consent was obtained from all patients in PsoBest and GPS-Best and that PsoBest and GPS-Best (parts A and B) were conducted in accordance with the ethical standards of the responsible committees (institutional or regional) and with the Helsinki Declaration of 1975, as revised in 1983.

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Author Contributions

All authors made a significant contribution to the work reported, whether that was in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; taking part in drafting, revising or critically reviewing the article; agreeing on the journal to which the article has been submitted; giving final approval of the version to be published; and agreeing to take responsibility for and be accountable for the contents of the article.

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Disclosure

Toni Maria Janke, Rachel Sommer, Christina Sorbe, and Thomas Bickert, have no conflicts of interest to declare.

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