

## Patient-relevant treatment goals in psoriasis

Christine Blome<sup>1</sup> · Ramona Gosau<sup>1</sup> · Marc A. Radtke<sup>1</sup> · Kristian Reich<sup>2</sup> ·  
Stephan J. Rustenbach<sup>1</sup> · Christina Spehr<sup>1</sup> · Diamant Thaçi<sup>3</sup> · Matthias Augustin<sup>1</sup>

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**Abstract** Patient-oriented care requires therapeutic decisions to agree with the patients' treatment needs and goals. This study addressed the following questions: What is important to psoriasis patients starting systemic treatment? How stable are these preferences within the first year of treatment? Are treatment goals associated with age, gender, or treatment success? The importance of treatment goals was assessed for patients with moderate-to-severe psoriasis in the German Psoriasis Registry (PsoBest) at baseline (onset of a systemic treatment;  $n = 3066$ ) and at a 1-year follow-up ( $n = 1444$ ) using the Patient Benefit Index (PBI). Treatment success was measured with PBI global score and Psoriasis Area Severity Index (PASI). Patients with moderate-to-severe psoriasis pursued a wide range of different goals. The most general treatment goals were rated most relevant, including skin healing and quick skin improvement (94.8/94.5 % “quite” or “very” important), confidence in the therapy (93.0 %), control over the disease (92.3 %), and a clear diagnosis and therapy (89.6 %). Further important goals related to not being in fear of the disease getting worse (84.8 %), reduction in itching (83.9 %), burning (70.6 %), and pain (60.6 %) as well as attaining a normal everyday life (78.4 %) and low

treatment burden (64.2–77.9 %). Goals were mostly not associated with sex and gender. Goal importance slightly increased with treatment success. In a substantial proportion of patients (30.3–54.7 %) goal importance changed within 1 year after onset of systemic treatment. We conclude that treatment goal importance should be assessed in clinical practice on a regular basis.

**Keywords** Psoriasis · Patient preferences · Treatment goals · Patient Benefit Index · Health-related quality of life

### Introduction

Psoriasis affects 2–4 % of the population [14, 18], while moderate-to-severe psoriasis accounts for more than 25 % of all cases seen in dermatological care [20].

Strategies that are currently recommended for psoriasis management sometimes tend to be technical in nature and regard people with the disease as a homogeneous population with a similar clinical progression and a similar likelihood of treatment success [11]. Other guidelines emphasize that treatment choices are tailored to the individual patient's needs and preferences (e.g., [9, 10]). Clinical experience shows that patients differ widely with individual disease expressions and personal perceptions of disease burden and treatment success. What also differs are systemic and biological agents used to control psoriasis, with regard to efficacy, degree of toxicity, treatment effort, and cost. Therefore, patient-oriented care demands for physicians to align the choice of psoriasis medication with preferences and treatment goals of each patient.

Psoriasis can impact a patient's life in various ways [8], including social stigmatization, physical disability, and

✉ Christine Blome  
c.blome@uke.de

<sup>1</sup> German Center for Health Services Research in Dermatology (CVderm), Institute for Health Services Research in Dermatology and Nursing (IVDP), University Medical Center Hamburg-Eppendorf (UKE), Martinistraße 52, 20246 Hamburg, Germany

<sup>2</sup> Dermatologikum Hamburg, Hamburg, Germany

<sup>3</sup> Comprehensive Center for Inflammation Medicine, University of Lübeck, Lübeck, Germany

emotional distress [4, 15]. Patients experience a similar or even greater reduction of health-related quality of life as compared to persons with other major diseases such as cancer or diabetes [16]. It can be assumed that the more intense an impairment becomes (e.g., itch intensity), the more the importance of the respective treatment goal will increase (e.g., to reduce itching). On the other hand, patients' treatment goals may be determined by other factors such as general attitudes or fear of future impairments, implying that goal importance should be measured in addition to health-related quality of life in order to determine the patient's preferences. In patients with nail psoriasis it has been found that treatment goal importance is not redundant to quality of life, and goal importance may be high even in patients with relatively low impairment [3].

Patient orientation is central not only to patient care, but also to clinical and health services research. Knowledge of treatment effects that are actually important to patients with psoriasis can only be created if studies assess patient-relevant outcomes. This needs to be done by the patients themselves, as physicians' and patients' assessments can differ markedly [22].

The importance and achievement of treatment goals in psoriasis can be measured with the Patient Benefit Index (standard version for chronic skin diseases, PBI-S). A list of 25 different treatment goals is rated for importance in the first part of the PBI-S, the Patient Needs Questionnaire (PNQ). In the second part, the Patient Benefit Questionnaire (PBQ), patients evaluate the benefit of their current treatment by rating the achievement of these goals. A preference-weighted global benefit score can be calculated from all items of PNQ and PBQ [1]. The PBI treatment goal items were developed on the basis of an open survey of 100 patients with chronic skin diseases, including psoriasis, where participants described relevant impairments and important treatment goals in their own words. Based on this survey, an expert panel of dermatologists specializing in psoriasis, psychologists, health economists, and patients developed standardized treatment goals for the PBI-S [1]. The questionnaire has been validated for use in patients with different skin diseases [1], as well as for patients with psoriasis [5].

Using PBI-S data obtained from the German psoriasis registry "PsoBest" [2], this study aimed to determine the importance of treatment goals for patients receiving systemic treatment and whether importance differs by age and gender. We further aimed to determine how stable the goals remain within the first year of treatment, and how this relates to treatment success as measured with the PASI-75 and the PBI global score. Patient preferences that do not persist would imply that physicians should address their

patients' goals on a regular basis and maybe readjust treatment to changing preferences.

## Methods

### Assessment of treatment goals in the psoriasis registry PsoBest

The PBI-S was implemented in the German Psoriasis Registry PsoBest [2]. PsoBest assesses long-term efficacy, safety, patient benefit, and treatment regimens of psoriasis. Patient registries provide long-term observational data on health care and treatment outcomes in real-world settings, thus complementing data from randomized clinical trials, which are characterized by restrictive inclusion criteria and non-representative treatment settings. According to a systematic review by Eissing et al. (manuscript under submission), there are currently 14 psoriasis registries worldwide including the international PSOLAR [13], the Italian PsoCare [7] and the British BADBIR [21], with patients' treatment goals uniquely being assessed in the German Psoriasis Registry PsoBest.

Adult patients with moderate or severe psoriasis treated in dermatological practices or clinics are included in the registry PsoBest when they receive a systemic drug including biologics for the first time (i.e., they have to be naive for the inclusion medication). The majority have previously received other systemic treatments. Patients are followed for 10 years, independent of their continuation of the initial treatment. The PNQ is assessed at the first visit (baseline) and again after about 1 year at visit 4 (follow-up). All patients gave informed consent.

The analysis reported here includes all patients with cleaned baseline data until 31 December 2013. For a subset of these patients, visit 4 had also been conducted until 31 December 2013 so that follow-up data were available.

For each treatment goal item in the PNQ, mean importance at baseline was determined. The response "does not apply to me" was coded as zero (0) and, thereby, put on a level with the response "not at all important" since in both cases the goal was irrelevant for the patient. In addition, the percentage of patients who stated the goal was "quite" or "very" important was determined.

Average treatment goal importance was compared for men versus women, and for patients younger than 50 years of age versus patients aged 50 or older, using t-tests for independent samples without adjusting the significance level of  $p = 0.05$  for multiple testing, as this was an exploratory analysis.

Clinical data as reported by the physicians at baseline were analyzed descriptively.

Using the follow-up data, stability of importance ratings was determined as the percentage of patients who gave the same importance rating at visit 1 (inclusion) and visit 4 (month 12). In the case that the rating had changed, it was further distinguished between those with a higher and those with a lower importance rating. The analyses were performed for every single goal, as well as for the average importance over all goals at one point in time (baseline and follow-up).

An additional analysis looked at all PNQ responses of all patients at baseline; that is, without differentiating by treatment goal. For each possible response at baseline (not at all, somewhat, etc.), the distribution of follow-up responses was determined.

In order to determine the association between treatment success and changes in goal importance, we compared the percentage of patients for whom goal importance had decreased from baseline to follow-up among those who had achieved PASI-75 as compared to those who had not. PASI-75 was achieved when the PASI score at follow-up had decreased by at least 75 % since baseline. In addition, the change in goal importance from baseline to follow-up was correlated with the PBI global score on patient-relevant treatment benefit (Pearson's correlation coefficient). We hypothesized that with successful treatment, goals would become less important to the patients.

Data analysis was performed with IBM SPSS statistics version 22.

## Results

### Assessment of treatment goals in the psoriasis registry PsoBest

There were 3066 patients who completed the PNQ at baseline (out of 3166 patients registered in PsoBest) (Table 1). PNQ data were also available at follow-up for 1444 patients. On average, the follow-up visit was  $378 \pm 41$  days after the baseline visit. Mean age at baseline was 47.2 years; 59.6 % were male. On average, the first diagnosis had been 18.3 years before. The average PASI score [6] score was  $14.5 \pm 9.6$ , which corresponds to moderate-to-severe disease.

### Treatment goals of patients under systemic treatment

All treatment goals were rated as “quite” or “very” important by the majority of patients (Table 2), except for item no. 13 on working life with 49.5 % approval. The most general treatment goals were rated most relevant, with skin healing and quick improvement of the skin as the most important goals (94.8/94.5 %), followed by confidence in the therapy (93.0 %), control over the disease (92.3 %), and a clear diagnosis and therapy (89.6 %). For 84.8 % of the patients, not being in fear of the disease getting worse was particularly important.

**Table 1** Clinical and sociodemographic patient characteristics (baseline)

	Patients with baseline data	Patients with follow-up data
<i>n</i>	3066	1444
Sex		
Male ( <i>n</i> , %)	1827 (59.6 %)	847 (58.7 %)
Female ( <i>n</i> , %)	1239 (40.4 %)	597 (41.3 %)
Age		
Mean $\pm$ SD	47.2 $\pm$ 14.3	48.1 $\pm$ 13.6
Range	18–88	18–85
Years since first diagnosed with psoriasis		
Mean $\pm$ SD	18.3 $\pm$ 14.2	19.5 $\pm$ 14.0
Range	0–75	0–75
PASI		
Mean $\pm$ SD	14.5 $\pm$ 9.6	14.6 $\pm$ 9.9
Range	0.0–66.6	0–66.6
Psoriatic arthritis <sup>a</sup>		
Yes or likely ( <i>n</i> , %)	673 (22.0 %)	354 (24.5 %)
No or unlikely ( <i>n</i> , %)	2393 (78.0 %)	1090 (75.5 %)

*n* number of patients, *SD* standard deviation number of patients, *PASI* Psoriasis Area and Severity Index, *NA* not assessed

<sup>a</sup> Psoriatic arthritis was considered to be present if diagnosed by a physician and was considered likely based on the study physician's evaluation and repeated presence of enthesitis or dactylitis

**Table 2** Importance of treatment goals according to the Patient Needs Questionnaire, ordered by % of patients stating quite or very high importance

Item number and wording	Baseline			Follow-up after about 1 year							<i>p</i> *	
	<i>n</i>	Goal is “quite” or “very” important (%)	Goal importance: Mean	Goal importance: SD	<i>n</i>	Importance rating equal to baseline (%)	Importance rating has changed (%)	Goal has become less important (%)	Goal has become more important (%)	Goal has become less important (% of patients with PASI-75)		Goal has become less important (% of patients without PASI-75)
(04) To be healed of all skin defects	3023	94.8	3.72	0.72	1412	69.3	30.7	19.6	11.1	18.2	21.7	0.109
(24) To get better skin quickly	3052	94.5	3.73	0.68	1426	69.7	30.3	19.0	11.3	18.2	20.5	0.289
(23) To have confidence in the therapy	3035	93.0	3.65	0.84	1406	67.7	32.3	19.3	13.0	18.3	21.3	0.178
(25) To regain control of the disease	3027	92.3	3.62	0.88	1416	66.4	33.6	19.1	14.5	19.6	18.8	0.723
(22) To find a clear diagnosis and therapy	3027	89.6	3.54	1.05	1406	65.1	34.9	21.4	13.5	18.5	24.7	<b>0.006</b>
(08) To have no fear that the disease will become worse	3024	84.4	3.37	1.14	1416	56.5	43.5	24.9	18.6	25.8	23.9	0.404
(02) To be free of itching	3044	83.9	3.33	1.24	1427	62.7	37.3	20.3	17.0	18.8	21.7	0.181
(09) To be able to lead a normal everyday life	3033	78.4	3.09	1.39	1423	53.1	46.9	25.2	21.7	22.1	28.3	<b>0.008</b>
(19) To need less time for daily treatment	3029	77.9	3.15	1.20	1412	47.0	53.0	30.5	22.5	27.5	33.7	<b>0.013</b>
(18) To be less dependent on doctor and clinic visits	3037	77.8	3.16	1.22	1420	49.4	50.6	27.5	23.0	25.8	29.8	0.100
(07) To experience a greater enjoyment of life	3012	76.8	3.04	1.44	1399	52.8	47.2	27.8	19.4	25.8	30.0	0.086
(15) To be comfortable showing yourself more in public	3033	75.2	3.03	1.40	1414	52.3	47.7	25.6	22.1	24.3	26.9	0.278
(12) To be able to engage in normal leisure activities	3027	72.3	2.90	1.52	1414	49.9	50.1	29.6	20.4	27.7	32.1	0.079

Table 2 continued

Item number and wording	Baseline		Follow-up after about 1 year							<i>p</i> *		
	<i>n</i>	Goal is “quite” or “very” important (%)	Goal importance: Mean	Goal importance: SD	<i>n</i>	Importance rating equal to baseline (%)	Importance rating has changed (%)	Goal has become less important (%)	Goal has become more important (%)		Goal has become less important (% of patients with PASI-75)	Goal has become more important (% of patients without PASI-75)
(03) To no longer have burning sensations on your skin	2991	70.6	2.81	1.63	1407	56.6	43.4	21.3	22.1	19.2	24.0	<b>0.031</b>
(21) To have fewer side effects	3014	68.5	2.80	1.54	1408	48.2	51.8	22.6	29.2	21.8	22.9	0.635
(20) To have fewer out-of-pocket treatment expenses	3025	64.2	2.72	1.51	1405	45.3	54.7	27.9	26.8	25.9	29.9	0.100
(01) To be free of pain	2966	60.6	2.41	1.79	1391	57.4	42.6	20.3	22.3	18.2	23.0	<b>0.030</b>
(10) To be more productive in everyday life	3006	59.3	2.40	1.70	1412	50.4	49.6	25.2	24.4	23.5	26.6	0.188
(06) To feel less depressed	3011	58.6	2.41	1.66	1408	47.1	52.9	25.9	27.0	23.1	29.1	<b>0.013</b>
(16) To be less burdened in your partnership	3022	58.3	2.37	1.72	1415	49.7	50.3	28.6	21.7	26.5	30.6	0.093
(11) To be less of a burden to relatives and friends	3024	54.9	2.31	1.68	1417	47.2	52.8	28.0	24.8	25.7	30.6	<b>0.042</b>
(17) To be able to have a normal sex life	3007	54.1	2.21	1.76	1400	51.8	48.2	25.9	22.3	24.4	27.6	0.179
(14) To be able to have more contact with other people	3008	51.1	2.14	1.71	1404	46.3	53.7	22.5	31.2	21.3	23.3	0.378
(05) To be able to sleep better	3003	50.3	2.08	1.75	1399	49.4	50.6	23.1	27.5	21.0	24.8	0.094
(13) To be able to lead a normal working life	3002	49.5	2.01	1.81	1400	58.1	41.9	21.9	19.9	18.6	25.9	<b>0.001</b>
Average over all items		71.6	2.88	1.40		54.8	45.2	24.1	21.1	22.4	26.1	

Baseline: assessment at the onset of a new systemic treatment of psoriasis; follow-up: assessment after about 1 year; range: 0–4 with 0 = not at all important or not applicable to 4 = very important

*n* number of patients, *SD* standard deviation, *p* level of significance; significant values in bold

\* Two-sided significance of Chi-square test comparing the percentage of patients with need reduction in those with PASI-75 vs. those without PASI-75

Among the goals related to a reduction of physical psoriasis symptoms, itching was most important (83.9 %), followed by burning sensations (70.6 %) and pain (60.6 %). With regard to functioning, being able to lead a normal everyday life (78.4 %) was rated more important than productivity in everyday life (59.3 %) and having a normal work life (49.5 %).

Goals aiming at a low burden due to the treatment itself were also regarded highly relevant, with time needed for daily treatment being most important (77.9 %), followed by visits to physicians and clinics (77.8 %), side effects (68.5 %), and out-of-pocket treatment expenses (64.2 %). In comparison, patients assigned lower importance to psychosocial goals, albeit with still high approval of 51.1 % (contact with other people) up to 76.8 % (greater enjoyment of life).

Women assigned significantly higher importance than men to 19 out of 25 treatment goals (Table 3), but most differences were small, ranging from 0.07 to 0.64 points on the five-point scale. The largest differences were found for goal 6 “to feel less depressed” (2.79 in women vs. 2.16 in men) and goal 5 “to be able to sleep better” (2.34 in women vs. 1.90 in men), which is concordant with the higher prevalence of depression [19] and insomnia [12] in women.

To patients older than 50 years, it was significantly less important “to be able to lead a normal working life” (1.62 vs. 2.30), which is probably due to many patients not working anymore. Three further goals had significantly less importance for older patients, but differences were small (<0.25 points on the five-point scale). Eleven goals were significantly more important to younger patients, again with rather small differences between 0.05 and 0.33, with the largest differences in goal 5, “to be able to sleep better”, goal 1, “to be free of pain”, and goal 21, “to have fewer side effects”.

### Stability of treatment goals over 1 year

The five most stable goals—with more than 65 % of patients giving equal importance ratings at baseline and follow-up—were also those regarded as most important at baseline (Table 2). In contrast, the least stable goals were those relating to burden of treatment (time effort, patient expenses, visits to physicians) on the one hand and psychosocial goals on the other hand, including depressiveness, burden on partnership and family, and contact with other people.

For most items (19 out of 25) there were more patients with a decrease than with an increase in importance rating. In some goals, however, a higher proportion of patients stated increased importance at follow-up, particularly regarding “to be able to have more contact with other

people” (22.5 % less important/31.2 % more important), “to have fewer side effects” (22.5 % less/31.2 % more) and “to be able to sleep better” (23.1 % less/27.5 % more).

When averaged across all treatment goals, constant importance ratings prevailed with 54.8 % of patients. On average a decrease in importance was found in 24.1 % of patients, which was slightly more often than an increase (21.1 %).

Looking at the total of 35,460 importance ratings at baseline, without differentiating by treatment goal, it was found that by far the most prevalent response at both baseline and follow-up was “very” important (57.6 %/55.8 % of responses; Tables 4, 5). Consequently, patients stating importance of any degree at baseline (i.e., somewhat, moderately, quite, or very) most often changed to “very” at follow-up, and the baseline response of “very” was the only category that was stable in the majority of cases.

Those who chose “not at all” important at baseline predominantly changed to “does not apply to me”, whereas those stating “does not apply to me” already at baseline most often stayed with this response option after 1 year.

Overall, 53.6 % of all response pairs (baseline–follow-up) consisted of two identical responses. This is also due to the high share of the response “very,” which stayed stable in 70.0 % of baseline cases (14,293 in 20,428 responses).

There was only a very small association between change in goal importance and overall treatment benefit according to the PBI global score at follow-up ( $r = 0.03$ – $0.16$ ), but the correlations were statistically significant for all but three treatment goals due to the large sample size. The positive coefficients indicate that with higher benefit, goals became slightly more important on average.

There were more patients with a reduction in importance among those who did not achieve PASI-75 than among those who did achieve PASI-75; this was statistically significant for 8 in 25 items (Table 2). This effect was most pronounced for the goal “to be able to lead a normal working life” with 25.9 % need reduction in patients without PASI-75 vs. 18.6 % need reduction in patients with PASI-75.

## Discussion

In this study, we looked at treatment goals in patients with psoriasis and stability in treatment goals in order to inform clinical practice and clinical study design.

The first question we addressed concerned the importance of different treatment goals from the perspective of patients receiving systemic treatment. We found that the patients who suffered from moderate-to-severe psoriasis

**Table 3** Association of average treatment goal importance with sex and age at baseline

Item number and wording	Male			Female			$\Delta^a$	<i>p</i>	Age <50 years			Age ≥50 years			$\Delta^b$	<i>p</i>
	<i>n</i>	Mean	SD	<i>n</i>	Mean	SD			<i>n</i>	Mean	SD	<i>n</i>	Mean	SD		
(01) To be free of pain	1767	2.31	1.79	1199	2.57	1.78	0.26	<0.001	1671	2.28	1.81	1292	2.60	1.75	0.32	<0.001
(02) To be free of itching	1813	3.25	1.27	1231	3.43	1.18	0.18	<0.001	1706	3.33	1.20	1335	3.32	1.29	-0.02	0.682
(03) To no longer have burning sensations on your skin	1786	2.70	1.66	1205	2.97	1.57	0.27	<0.001	1687	2.82	1.61	1301	2.79	1.66	-0.03	0.659
(04) To be healed of all skin defects	1798	3.70	0.75	1225	3.76	0.68	0.07	0.012	1697	3.73	0.69	1323	3.72	0.76	-0.01	0.739
(05) To be able to sleep better	1795	1.90	1.73	1208	2.34	1.74	0.44	<0.001	1685	1.93	1.72	1315	2.26	1.77	0.33	<0.001
(06) To feel less depressed	1792	2.16	1.67	1219	2.79	1.56	0.64	<0.001	1687	2.43	1.62	1321	2.39	1.70	-0.04	0.485
(07) To experience a greater enjoyment of life	1800	2.93	1.48	1212	3.19	1.37	0.25	<0.001	1684	3.04	1.41	1326	3.03	1.49	-0.01	0.835
(08) To have no fear that the disease will become worse	1804	3.31	1.18	1220	3.45	1.08	0.14	0.001	1691	3.36	1.11	1330	3.38	1.18	0.02	0.601
(09) To be able to lead a normal everyday life	1810	3.05	1.40	1223	3.16	1.38	0.11	0.035	1697	3.08	1.37	1333	3.11	1.42	0.03	0.545
(10) To be more productive in everyday life	1799	2.26	1.71	1207	2.61	1.65	0.35	<0.001	1684	2.27	1.71	1319	2.56	1.67	0.28	<0.001
(11) To be less of a burden to relatives and friends	1807	2.26	1.68	1217	2.40	1.69	0.14	0.025	1691	2.21	1.66	1330	2.44	1.70	0.23	<0.001
(12) To be able to engage in normal leisure activities	1811	2.86	1.52	1216	2.96	1.51	0.10	0.890	1698	2.85	1.51	1326	2.97	1.52	0.12	0.037
(13) To be able to lead a normal working life	1793	2.01	1.80	1209	2.00	1.84	-0.02	0.799	1696	2.30	1.74	1303	1.62	1.84	-0.68	<0.001
(14) To be able to have more contact with other people	1799	2.12	1.70	1209	2.16	1.73	0.04	0.497	1688	2.11	1.68	1317	2.16	1.75	0.05	0.441
(15) To be comfortable showing yourself more in public	1808	2.92	1.43	1225	3.19	1.35	0.27	<0.001	1697	3.13	1.31	1333	2.91	1.51	-0.22	<0.001
(16) To be less burdened in your partnership	1797	2.34	1.70	1225	2.42	1.74	0.07	0.251	1696	2.44	1.68	1323	2.29	1.77	-0.15	0.016
(17) To be able to have a normal sex life	1793	2.23	1.74	1214	2.18	1.78	-0.05	0.481	1694	2.32	1.73	1310	2.07	1.78	-0.25	<0.001
(18) To be less dependent on doctor and clinic visits	1812	3.13	1.21	1225	3.20	1.22	0.07	0.132	1697	3.05	1.24	1337	3.29	1.17	0.24	<0.001
(19) To need less time for daily treatment	1807	3.11	1.21	1222	3.20	1.19	0.09	0.035	1700	3.14	1.18	1326	3.16	1.23	0.03	0.511
(20) To have fewer out-of-pocket treatment expenses	1802	2.67	1.50	1223	2.79	1.52	0.12	0.035	1696	2.65	1.51	1326	2.81	1.51	0.16	0.004
(21) To have fewer side effects	1800	2.71	1.56	1214	2.95	1.50	0.24	<0.001	1687	2.67	1.55	1324	2.97	1.50	0.30	<0.001
(22) To find a clear diagnosis and therapy	1808	3.49	1.06	1219	3.60	1.02	0.11	0.003	1694	3.47	1.09	1330	3.62	0.99	0.16	<0.001
(23) To have confidence in the therapy	1811	3.59	0.89	1224	3.73	0.75	0.14	<0.001	1696	3.57	0.89	1336	3.75	0.76	0.18	<0.001
(24) To get better skin quickly	1817	3.68	0.74	1235	3.79	0.60	0.11	<0.001	1705	3.70	0.69	1344	3.76	0.68	0.05	0.039
(25) To regain control of the disease	1801	3.57	0.90	1226	3.69	0.83	0.11	<0.001	1692	3.59	0.87	1332	3.65	0.89	0.06	0.065

Bold numbers: *p* < 0.05; range of goal importance: 0 = not at all important or does not apply to 4 = very important

*p* level of significance according to *t* test for independent samples, *n* number of patients, *SD* standard deviation

<sup>a</sup> Difference between group means: positive values indicate higher importance in women than in men

<sup>b</sup> Difference between group means: positive values indicate higher importance in older patients than in younger patients

**Table 4** Cross-table on all responses to importance ratings in the PBI-S at baseline and 1-year follow-up without differentiating by treatment goal, indicating switches and persistent answers (number of responses)

		Follow-up						
		Not at all	Somewhat	Moderately	Quite	Very	Does not apply	Total
Baseline	Not at all	86	72	62	71	184	294	769
	Somewhat	67	136	147	271	327	307	1255
	Moderately	53	170	304	514	820	466	2327
	Quite	88	233	407	1480	2775	793	5776
	Very	172	387	812	2998	14293	1766	20428
	Does not apply	128	113	172	404	1379	2709	4905
	Total	594	1111	1904	5738	19778	6335	35460

**Table 5** Cross-table on all responses to importance ratings in the PBI-S at baseline and 1-year follow-up without differentiating by treatment goal, indicating switches and persistent answers (as percentage of baseline response)

		Follow-up						
		Not at all	Somewhat	Moderately	Quite	Very	Does not apply	Total
Baseline	Not at all	11.2	9.4	8.1	9.2	23.9	38.2	100.0
	Somewhat	5.3	10.8	11.7	21.6	26.1	24.5	100.0
	Moderately	2.3	7.3	13.1	22.1	35.2	20.0	100.0
	Quite	1.5	4.0	7.0	25.6	48.0	13.7	100.0
	Very	0.8	1.9	4.0	14.7	70.0	8.6	100.0
	Does not apply	2.6	2.3	3.5	8.2	28.1	55.2	100.0
	Total	1.7	3.1	5.4	5.4	55.8	17.9	

pursued a wide range of different outcomes with almost all 23 goals being of high importance to more than 50 % of respondents. In addition to very general treatment goals such as skin healing, patients particularly wished for a reduction in itching, burning and pain, a normal everyday life, and treatment that did not constitute an additional burden. Differences regarding sex and age were mainly small, with the largest differences being little surprising: women placed more importance on sleep and depression, and younger patients placed more importance on working life.

The achievement of these goals should be measured in clinical trials, since only data on outcomes that are highly important to patients allow for inferences about the actual patient-relevant benefit of the intervention studied. For the same reason physicians in clinical practice should ask patients about their treatment goals (and the achievement of these goals) instead of relying on clinical assessment only. In contrast, physician-reported measures such as the PASI are not patient-relevant in itself, and have been found

to only partially correspond with benefits reported by patients [17].

Our second question addressed the stability of patients' treatment goals. Overall, we found that goal importance ratings tended to decrease within the first year of systemic treatment, which might indicate that effective systemic treatment reduces patient need and thereby goal importance. There was, however, a substantial proportion of patients whose importance ratings remained unchanged or even increased with time. This could be explained by incomplete goal achievement—or by goals remaining important even after they have been achieved, possibly with the patient hoping for the treatment benefit to persist. It can also be argued that with goal achievement, some areas of impairment may become even more important to patients: when enduring a limitation for a long time, many patients may resign and not hope for change anymore, such as when they withdraw from social life as a result of perceived stigmatization. Once they experience that an improvement is possible (e.g., when systemic treatment has



alleviated visible skin lesions), this may revive their wish to be in contact with other people.

Contrary to expectations, we did not find that goals became less important with successful treatment as measured with the physician-reported PASI-75 and the patient-reported PBI global score on treatment benefit. Instead, we found a tendency that goal importance increased with treatment success, but effect sizes were rather small. Future, qualitative research could look at reasons for this surprising behavior: does the persisting goal importance reflect a fear that former impairments will reoccur; or does goal achievement induce the wish for even more improvement? In addition, we recommend to address the role of specific conditions such as depression or psoriasis-arthritis in patients' treatment goals in future studies.

The finding that goals relating to treatment burden were among the least stable was not surprising as treatment had been changed at study baseline and, thereby, the burdens of treatment had in many cases also changed.

Looking at the overall responses to all 25 treatment goals, we found that patients most often chose "very important" at both baseline and follow-up assessment. The high percentage of patients who changed from "not at all important" to "does not apply to me" may indicate that they found it difficult to distinguish between these two options as in either case the respective goal was irrelevant for the current treatment. An alternative explanation is that systemic treatment was effective enough to eliminate low-intensity impairments, which were of low importance to patients, with the result that the goal no longer applied after the first year of treatment (which included one or more medications, as many patients changed treatment one or more times between baseline and follow-up).

For clinical practice, our findings imply that physicians should assess their patients' treatment goals in addition to assessing current symptoms and quality of life impairments. Moreover, patients' needs should be re-assessed on a regular basis during the treatment process, as preferences may change and new ones may emerge; even when PASI-75 has been achieved, goals continue to be important to patients.

Our study is limited by the fact that the size of a correlation, statistically, does not depend only on the association between the two constructs measured, but also on the variance and reliability of the variables. In this study, item variance differed markedly between items with 0.68–1.81 (possible range 0–4); this may explain part of the differences we found in effect size. Reliability of the single PNQ items is not known yet.

We analyzed data from the German Psoriasis Registry PsoBest, which includes a large number of patients treated in dermatological practices all over Germany without

intervening in routine care except for the data collection itself. These data can be assumed to have a high degree of representativeness for German psoriasis patients under systemic treatment. Most patients in the PsoBest registry had been diagnosed with psoriasis for a long time (18.3 years on average) and had received other systemic treatment before study inclusion. Future research should therefore look at treatment goals in patients who have only recently been diagnosed with psoriasis and/or receive a systemic treatment for the first time.

## Conclusions

Patients with moderate-to-severe psoriasis pursue a wide range of different treatment goals beyond skin clearance. Specific goals concerned itching, burning, and pain, a normal everyday life, and a low treatment burden. In a substantial proportion of patients the importance of treatment goals changed within 1 year after onset of a systemic treatment, but importance did not decrease with treatment success. Treatment goals should therefore be assessed on a regular basis in clinical practice in addition to measuring quality of life and clinical severity.

## Compliance with ethical standards

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**Conflict of interest** Blome C has received speaker honoraria, research grants, awards, and/or travel grants from Janssen-Cilag, Kreussler, Lilly, and medi. Gosau R has no conflicts of interest to declare. Radtke MA has received honoraria and travel expenses from Biogen, Pfizer, Abbvie, Celgene, Janssen, MSD, Amgen, Mundipharma, Leo, Almirall and Galderma. Reich K has served as consultant and paid speaker for and participated in clinical trials sponsored by companies that manufacture drugs used for the treatment of psoriasis including Abbvie, Amgen, Biogen, Elgene, Entocor, Ovagen, Forward Pharma, GSK, Janssen- ilag, Leo, Lilly, Medac, MSD, Novartis, Pfizer, Vertex, Takeda. Rustenbach SJ is an employee at the University Medical Center Hamburg-Eppendorf (UKE). Spehr C is an employee at the University Medical Center Hamburg-Eppendorf (UKE). Thaçi D has served as a consultant, investigator, and speaker, and has participated in advisory boards for AbbVie, Amgen, Biogen, Celgene, Eli Lilly, Janssen, Leo Pharma, MSD, Novartis, and Pfizer Inc; and has received research/educational Grants from Abbvie and Pfizer Inc. Augustin M has received honoraria and travel expenses from Abbott, Almirall, Amgen, Biogen, Celgene, Centocor, Janssen-Cilag, Leo, Medac, MSD (formerly Essex, Schering-Plough), Novartis, Pfizer (formerly Wyeth).

**Ethical approval** All procedures performed in studies involving human participants were in accordance with the ethical standards of

the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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