



# Despite large choice of effective therapies: Individuals with psoriasis still seem undertreated

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## Introduction

Psoriasis is a chronic, immune-mediated disorder with an estimated prevalence of 1–2.5 % in adults in Germany and a mean duration of disease of more than 50 years [1–3]. Clinical manifestation presents most frequently with erythematous plaques of the skin. Nowadays it is considered a systemic disease, displaying a vast number of physical and psychological comorbidities such as arthritis, cardio-vascular diseases, obesity, depression, anxiety, and addictions [4–6]. In affected patients, psoriasis is regarded as a substantial problem, leading to a significant reduction in quality of life and mental well-being [7–10]. Moreover, on a societal scale, psoriasis amounts to a great socio-economic burden [11].

In terms of treatment, physicians and patients may choose from various options resulting in highly promising physician-measured and patient-reported outcomes [12]. For

## Summary

**Background and objectives:** Due to the development of new anti-psoriatic drugs in combination with improved structures for implementation throughout Germany, the medical care of psoriasis patients has markedly improved. In this study we investigated the real-life utilization of the health care system and identified reasons for dissatisfaction in affected individuals.

**Patients and methods:** This non-interventional cross-sectional study was conducted as an anonymous online survey from 12/2018 to 01/2019 in Germany. Participants with a self-reported physician-confirmed diagnosis of psoriasis and symptoms answered questions about their disease, its influence on daily life and their medical care.

**Results:** 649 participants with a mean age of  $42.5 \pm 13.7$  years and equal gender distribution (male: 50.2 %) were evaluated. 54.1 % received medical treatment at the time of the study, 45.9 % did not. Among the participants with medical care, 59.3 % were only moderately or less satisfied with their treatment. Reasons for dissatisfaction with the medication included lack of efficacy and side effects. Participants without medical treatment specified a physician's lack of time as a main reason for not seeking medical help.

**Conclusions:** Despite the availability of efficient therapeutic options in Germany, many individuals with psoriasis are not satisfied. This under-treated group was identified as a new target population.

psoriasis patients in Germany, national goals on amelioration of medical care and several guidelines exist [1, 13–16]. They provide specific information about therapy goals, useful assessment tools for evaluation (for example Dermatology Life Quality Index (DLQI) and Psoriasis Area and Severity Index (PASI)), sequence of applicable medications as well as indicators for a need to switch therapeutics [1, 16]. Subsequently, health care of psoriasis patients in Germany has greatly improved in the last 15 years [11]. The World Health Organization even named Germany as a role model in their *Global report on psoriasis* in 2016 [17].

Nevertheless, gaps in the medical care of psoriasis patients still remain. According to recent studies, in Bavaria, Germany, approximately 50 % of individuals suffering from moderate to severe psoriasis are not in dermatological care [18] and only 15 % of patients with moderate to severe psoriasis are treated with biologics in dermatological practices

[19]. Additionally, only satisfied patients will stay in medical care [20]. Hence, it is important to identify factors that lead to satisfaction/dissatisfaction, not only from patients currently undergoing medical treatment, but also from affected individuals not consulting physicians regarding their psoriasis.

Therefore, the aim of this study was to investigate the impact of psoriasis on participants' lives in a person-centered manner, their level of satisfaction with their current physicians and therapies and to explore reasons for dissatisfaction with the received medication as well as reasons for not seeking medical treatment.

## Patients and methods

### Online survey and participants

This non-interventional cross-sectional study was designed by medical experts specialized in psoriasis (physicians and epidemiologists). The analysis was approved by the Ethics Committee of the Faculty of Medicine of the Technical University of Munich. It was conducted as an anonymous and voluntary online survey from December 2018 to January 2019 in Germany. Participants were recruited through online banner advertisements on Facebook and Google that stated: "Psoriasis Survey - participate now!" and "Psoriasis – looking for participants in a survey".

Participants had to be 18 years or older and had to read the patient information before actively giving their consent. To ensure data quality, only participants who reported that they had been diagnosed with psoriasis by a physician and presented symptoms within the last three months (scaling, plaques or itching) were included and consequently directed to the full questionnaire (Figure S1, online Supporting Information). Correctness of the psoriasis diagnosis or presence of other dermatological diagnosis was not verified by, for example, medical records, and no distinction was made between participants diagnosed by either a dermatologist or a primary-care physician.

### Questionnaire

All non-standardized questions were developed by a multi-disciplinary team of two dermatologists and two epidemiologists. The questionnaire included dichotomous, multiple choice and Likert scale questions as well as open questions. The latter were used to assess age, first three numbers of the postcode, duration of disease, time to diagnosis, affected body area and internet use. The average time to complete the questionnaire amounted to 11.3 min. The questionnaire was divided into three main parts: (1) participant characteristics; (2) influence of psoriasis on the daily life of participants; (3) medical care of participants, distinguishing between partici-

pants with or without current medical treatment.

Concerning the first part, participants were asked for their age, gender, time between onset and diagnosis, time since diagnosis, body area affected by psoriasis (measured using the palms of their hands) and affected body parts. Next, the influence of external factors on psoriasis and the impact on participants' daily lives and signs of depression were assessed. For the latter the Patient Health Questionnaire-2 (PHQ-2) was used [21, 22].

In addition, participants under therapy were asked about the type of physician consulted, the effectiveness of the physician's treatment as well as the type of therapy received and their satisfaction with it. Concerning participants without current treatment, reasons for not seeing a physician were investigated.

### Statistical analyses

Data analysis was performed using IBM SPSS Statistics (Version 25, IBM Corporation, Armonk, NY, USA). Implausible data sets were excluded from the analysis (for example disease duration, if age is less than the time since diagnosis; text instead of numbers for affected body area). Descriptive data was generated using the mean and standard deviation (mean  $\pm$  SD) as well as absolute numbers and proportions. Significance was examined using unpaired t-tests and chi-square tests and alpha was set at 0.05.

## Results

### Patient characteristics

A total of 649 participants (female: 49.8 %, male: 50.2 %) with a mean age of  $42.5 \pm 13.7$  years fulfilled the inclusion criteria and took the complete online survey. They displayed a mean duration of disease of  $18.1 \pm 12.7$  years ( $n = 612$ ) with 61.0 % ( $n = 396/612$ ) of the participants suffering from psoriasis for over ten years. The diagnosis was made at the mean age of  $28.2 \pm 15.3$  years after a mean time of  $3.6 \pm 5.4$  years after the appearance of symptoms.

Regarding individuals receiving medical care and those not being treated, those without professional treatment were younger (in years,  $41.0 \pm 13.7$  vs.  $43.7 \pm 13.7$ ;  $P = 0.013$ ), had an onset of disease at a younger age (in years,  $21.7 \pm 13.7$  vs.  $26.9 \pm 16.1$ ;  $P < 0.001$ ) and consequently a longer disease duration (in years,  $19.5 \pm 12.6$  vs.  $16.9 \pm 12.7$ ;  $P = 0.014$ ) (Table 1).

At the time of the survey 87.5 % ( $n = 568/649$ ) of the participants reported plaques, 77.2 % ( $n = 501/649$ ) scaling and 76.1 % ( $n = 494/649$ ) pruritus as active signs of psoriasis within the three previous months. No differences between participants with or without treatment were observed (Table 1).

**Table 1** Demographics and disease characteristics.

Characteristic	Medical treatment at time of study		All participants (n = 649)	P-Value <sup>#</sup>
	Yes (n = 351)	No (n = 298)		
<i>Demographics</i>				
Male gender, n (%)	179 (51.0 %)	147 (49.3 %)	326 (50.2 %)	0.672
Age in years, mean ± SD	43.7 ± 13.7	41.0 ± 13.7	42.5 ± 13.7	0.013
<i>Disease characteristics, mean ± SD</i>				
Disease duration in years*	16.9 ± 12.7	19.5 ± 12.6	18.1 ± 12.7	0.014
Time to diagnosis in years*	3.5 ± 5.3	3.7 ± 5.6	3.6 ± 5.4	0.669
Time since diagnosis in years*	13.5 ± 11.6	15.8 ± 12.7	14.5 ± 12.1	0.017
Age at disease onset in years*	26.9 ± 16.1	21.7 ± 13.7	24.6 ± 15.3	< 0.001
Age at disease diagnosis in years*	30.4 ± 15.8	25.4 ± 14.2	28.2 ± 15.3	< 0.001
<i>Symptoms within the previous 3 months, n (%)</i>				
Plaques	313 (89.2 %)	255 (85.6 %)	568 (87.5 %)	0.166
Scaling	270 (76.9 %)	231 (77.5 %)	501 (77.2 %)	0.857
Pruritus	263 (74.9 %)	231 (77.5 %)	494 (76.1 %)	0.441
Others	72 (20.5 %)	53 (17.8 %)	125 (19.3 %)	0.380
<i>Affected body parts</i>				
BSA**, mean ± SD	6.4 ± 8.0	5.7 ± 8.1	6.1 ± 8.0	0.261
Number of different body parts affected	4.9 ± 2.5	4.3 ± 2.6	4.6 ± 2.6	0.005
Head, n (% of cases)	257 (73.2 %)	202 (67.8 %)	459 (70.7 %)	0.129
Neck, n (% of cases)	33 (9.4 %)	19 (6.4 %)	52 (8 %)	0.157
Chest/Belly, n (% of cases)	132 (37.6 %)	106 (35.6 %)	238 (36.7 %)	0.592
Back, n (% of cases)	129 (36.8 %)	85 (28.5 %)	214 (33 %)	0.026
Arms, n (% of cases)	156 (55.6 %)	113 (37.9 %)	269 (41.4 %)	0.093
Elbows, n (% of cases)	229 (65.2 %)	196 (65.8 %)	425 (65.5 %)	0.888
Hands/Fingers, n (% of cases)	183 (52.1 %)	115 (38.6 %)	298 (45.9 %)	0.001
Legs, n (% of cases)	204 (58.1 %)	134 (45 %)	338 (52.1 %)	0.001
Knees, n (% of cases)	147 (41.9 %)	119 (39.9 %)	266 (41.0 %)	0.615
Feet, n (% of cases)	131 (37.3 %)	85 (28.5 %)	216 (33.3 %)	0.018
Anogenital, n (% of cases)	124 (35.3 %)	93 (31.2 %)	217 (33.4 %)	0.268
<i>Abbr.:</i> SD, standard deviation.				
*n = 612, others removed due to implausibility.				
**Body surface area (BSA); Measured with participants' palms; n = 645, others removed due to implausibility.				
<sup>#</sup> Unpaired t-test for metrically scaled variables and Pearson's chi-squared test for non-metrically scaled variables.				

The mean affected body surface area (BSA) amounted to 6.1 % ± 8.0 % (6.4 % ± 8.0 %; 5.7 % ± 8.1 %; *P* = 0.261; measured with the help of the participants' palms; n = 645). The most frequently affected areas in both groups were head

(73.2 %; 67.8 %) elbows (65.2 %; 65.8 %) and legs (58.1 %; 45.0 %). Furthermore, 33.4 % of the participants (35.3 %; 31.2 %) reported involvement of the anogenital area. Analyzing the number of different, affected body parts, participants

that underwent treatment at the time of the study displayed  $4.9 \pm 2.5$  body parts opposed to  $4.3 \pm 2.6$  ( $P = 0.005$ ) in participants without treatment (Table 1).

### Influence of psoriasis on daily life

A great majority of participants, regardless of their treatment status, reported a worsening of the skin due to external factors (80.3 %,  $n = 282/351$ ; 81.5 %,  $n = 243/298$ ) such as stress (private and at work), certain foods, physical effort or other factors.

In concordance with the identified aggravating external factors, participants of both groups avoid stressful situations (52.1 %,  $n = 183/351$ ; 41.6 %,  $n = 124/298$ ;  $P = 0.007$ ), have tried different diets (40.2 %,  $n = 141/351$ ; 35.2 %,  $n = 105/298$ ) and 35 % and 31.5 %, respectively, have stopped most of their physical activities. Additionally, about 40 % of participants (40.7,  $n = 143/351$ ; 38.3 %,  $n = 114/298$ ) often wear clothing that is too warm for the weather conditions in order to cover the whole body and about 23 % (22.2 %,  $n = 78/351$ ; 23.5 %,  $n = 70/298$ ) rarely go on vacation (Figure 1).

Concerning social life, 49.6 % ( $n = 174/351$ ) of participants with and 44.0 % of participants without treatment ( $n = 131/298$ ) presented a reduction of social contacts and activities. Hereby about 1/3 of both groups avoids physical proximity to friends (33.6 %,  $n = 118/351$ ; 34.2 %,  $n = 102/298$ ), and attends parties (34.8 %,  $n = 122/351$ ; 27.2 %,  $n = 81/298$ ) and meets friends (25.6 %,  $n = 90/351$ ; 25.2 %,  $n = 75/298$ ) less frequently due to their skin condition (Figure 1).

With regard to intimate relationships, about 75 % of both groups have a partner (75.5 %,  $n = 265/351$ ; 73.8 %,  $n = 220/298$ ) with about 95 % confirming that their partner understands their disease (93.6 %,  $n = 248/351$ ; 95.9 %,  $n = 211/298$ ).

Approximately 60 % (63.0 %,  $n = 221/351$ ; 62.1 %,  $n = 185/298$ ) of all participants have felt down, depressed or hopeless and about 50 % (54.1 %,  $n = 190/351$ ; 53.0 %,  $n = 158/298$ ) reported having little interest or pleasure in doing things in the month prior to the survey.

### Medical care of study participants

The group of participants receiving medical treatment at the time of the online survey represented 54.1 % of the study population ( $n = 351/649$ ), meaning that 45.9 % ( $n = 298/649$ ) were not under treatment (Figure S1, online Supporting Information). 83.9 % ( $n = 250/298$ ) of the latter group underwent medical treatment once after the diagnosis of psoriasis, but discontinued it.

Analyzing the medical professionals consulted by participants in current medical care, dermatologists were most

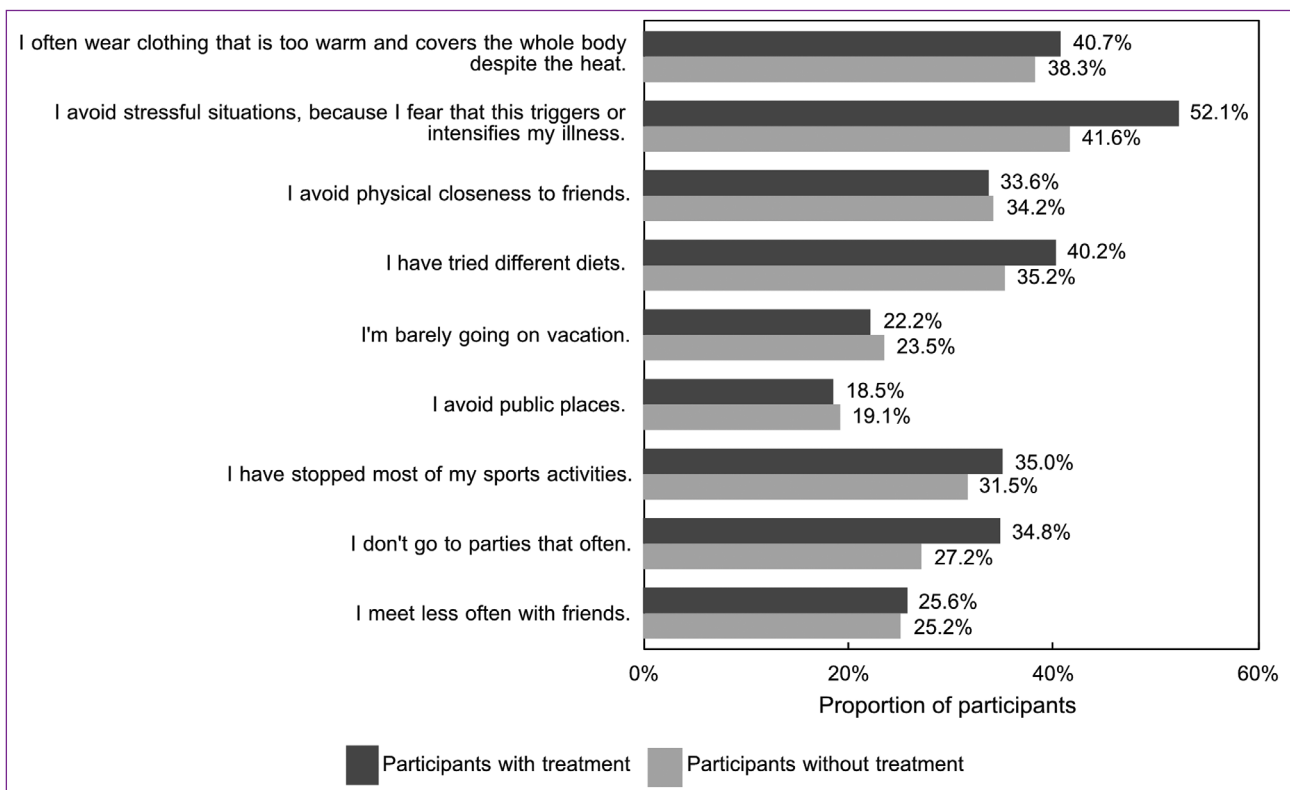


Figure 1 Influence of psoriasis on daily life.

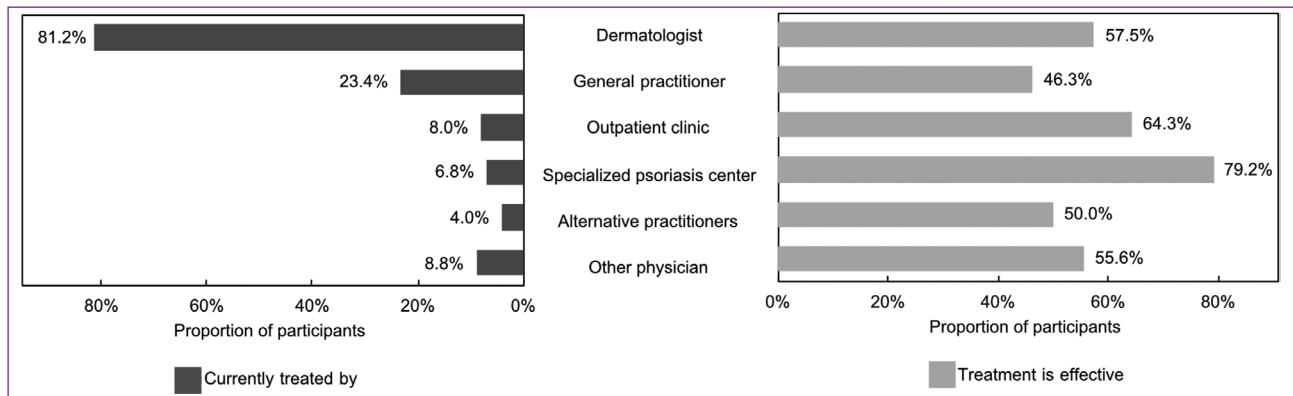


Figure 2 Current medical specialty consulted and effectiveness of treatment.

frequently visited (81.2 %; n = 285/351), followed by general practitioners (23.4 %; n = 82/351). Other practitioners (8.8 %), outpatient departments (8.0 %), specialized psoriasis centers (6.8 %) and naturopaths (4.0 %) were only consulted by a minority of participants. When evaluating whether treatment by the consulted professional was effective, 57.5 % (n = 153/266) of responses were affirmative for the dermatologist and 46.3 % (n = 38/82) were affirmative for the general practitioner. 79.2 % (n = 19/24) of the participants stated that treatment at a specialized psoriasis center is helpful (Figure 2).

Looking at the medication of the participants in current care, 94.9 % (n = 333/351) have prescription topical

medication, 55.8 % (n = 196/337) nonprescription topical products and 52.1 % (n = 183/351) have experience with UV/phototherapy. A systemic medication (tablets, infusions or injections) is/was applied in 50.4 % (n = 177/351) of the participants (oral therapy: 41.6 %, n = 146/351; subcutaneous/intravenous therapy: 23.9 %, n = 84/351) (Figure 3a). In the following, the patients were asked to state the level of overall satisfaction with the received treatment. 40.7 % (n = 143/351) were very satisfied (14.2 %, n = 50/351) or satisfied (26.5 %, n = 93/351), opposed to 59.3 % (n = 208/351) that were only moderately (34.5 %, n = 121/351), not (18.5 %, n = 65/351) or not at all (6.3 %, n = 22/351) satisfied (Figure 3b). When differentiating participants with systemic vs. without

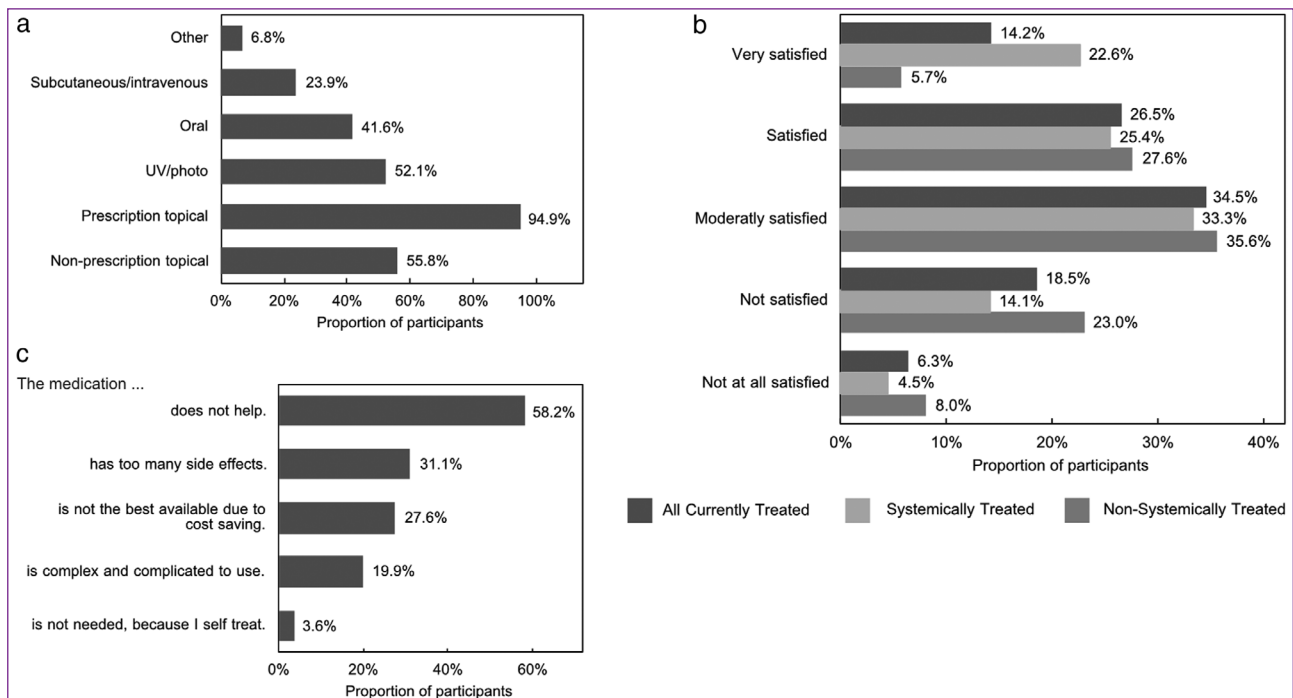
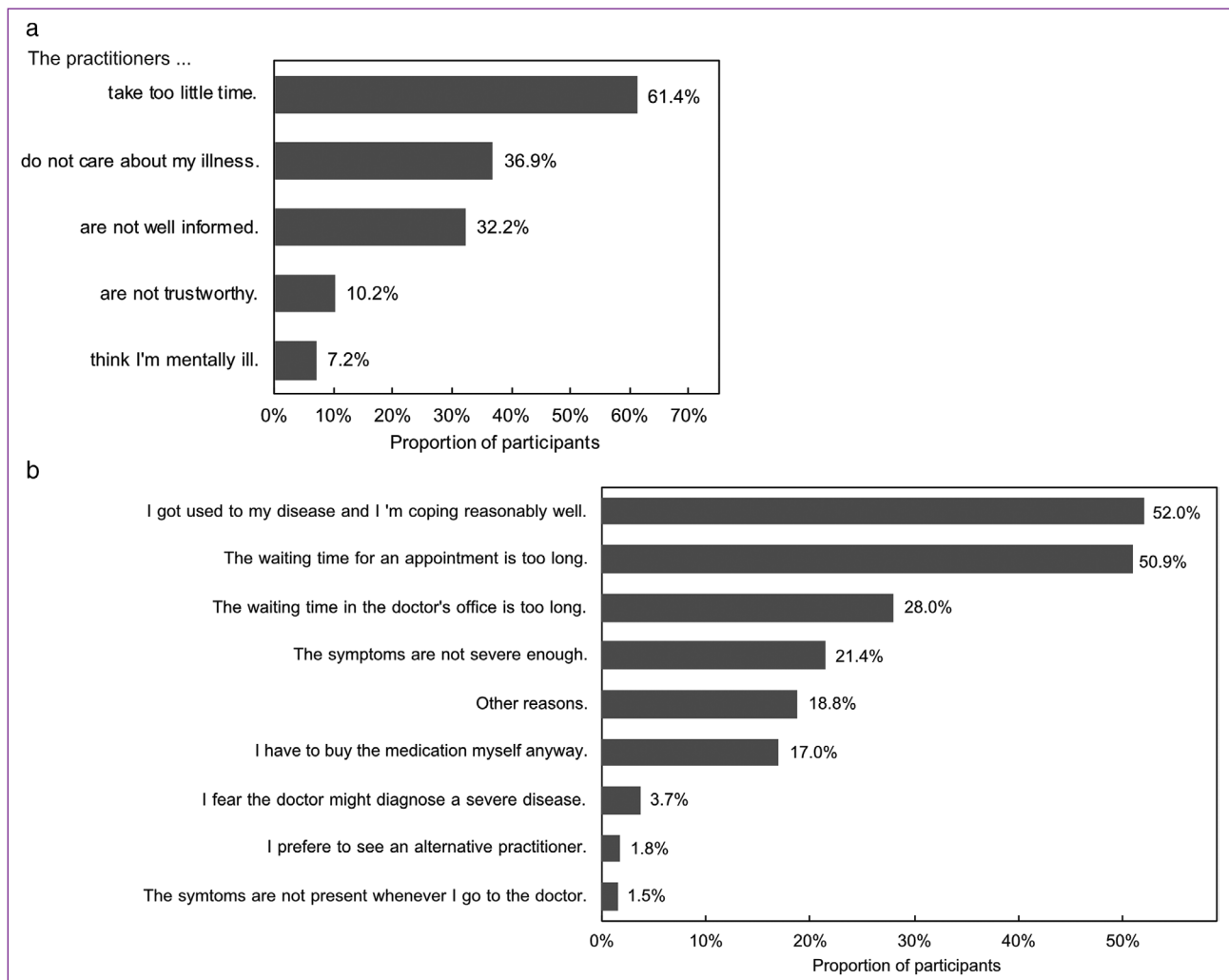


Figure 3 Treatment of participants receiving therapy at the time of the survey (a). Satisfaction with their therapy (b). Reasons for dissatisfaction with therapy (c).



**Figure 4** Physician-related (a) and additional factors (b) for not seeking professional medical care.

systemic treatment, the first group was significantly more satisfied than the latter ( $P < 0.001$ ) with more very satisfied (22.6 %,  $n = 40/177$ ; 5.7 %,  $n = 10/174$ ;  $P < 0.001$ ) and less not satisfied (14.1 %,  $n = 25/177$ ; 23.0 %,  $n = 40/174$ ;  $P < 0.03$ ) participants (Figure 3b). Reasons for the depicted dissatisfaction with the medication among the currently treated participants were investigated. 58.2 % ( $n = 114/196$ ) reported a lack of efficacy and 31.1 % ( $n = 61/196$ ) revealed that too many side effects were present. Furthermore, 27.6 % ( $n = 54/196$ ) had the impression that they did not get the best medication available due to cost-saving regimes and 19.9 % ( $n = 39/196$ ) noted that their medication is complex and complicated to use (Figure 3c).

Participants that did not consult physicians at the time of the study presented a number of physician-related and additional reasons for their choice. Regarding the physician, 61.4 % ( $n = 145/236$ ) reported that the medical professional had too little dedicated time and 36.9 % ( $n = 87/236$ ) had

the impression that the doctor was not interested in their disease. Moreover, 32.2 % ( $n = 76/236$ ) questioned the professional competence of the physician (Figure 4a). Additional reasons for not consulting a physician were that participants got used to their disease and were able to cope reasonably well (52.0 %,  $n = 141/271$ ), that waiting periods for appointments (50.9 %,  $n = 138/271$ ) and at an appointment (28.0 %,  $n = 76/271$ ) are too long and that symptoms are perceived as not severe enough (21.4 %,  $n = 58/271$ ) (Figure 4b).

## Discussion

The aim of the presented study was to assess satisfaction with treatments and reasons for not seeking medical professional care in individuals with psoriasis. Hereby, an astonishingly high proportion of 45.9 % of participants did not receive medical care at the time of the study. Of the remaining 54.1 %, almost 60 % were not satisfied with their current



treatment. The main given reason for not consulting a physician was the physician's lack of time.

Overall, distribution of sex aligned with previous literature [23, 24]. However, participants were about ten years younger than those of previous studies (mean age: 42.5 vs. 50.9 and 50.5 years) [24, 25]. Since the presented study was conducted as an online survey and internet usage decreases with age [26], the lower mean age appears logical. The observed lower age of disease onset of participants without treatment as well as their significantly longer disease duration as opposed to participants with treatment, render it possible that they acquired their experiences with the health care system earlier. They might have sought professional medical care before the new therapies were implemented in private practices and thereby simply missed the chance of excellent therapeutics. Concerning the active symptoms, no difference between both groups was observed and the provided distribution is in line with other studies [24]. Moreover, the well-known predilection sites were predominately affected in the whole study population as well as in both sub-populations [24]. The self-assessed body surface area (BSA) amounted to  $6.1 \% \pm 8.0 \%$ , displaying a moderate psoriasis in all analyzed groups [24]. The BSA calculation by using the palm of the participants' hands, may not reflect disease severity as well as the PASI, but correlates with the physician-assessed BSA [27]. Participants with treatment had more different body sites affected by psoriasis lesions than participants without treatment. A possible explanation is that participants actively treating their lesions might be more attentive towards their distribution. In summary, the acquired data on demographics and disease characteristics is consistent with data of several previous studies [23–25], which underlines a successful selection of the study population.

In addition, the study identifies a high burden of disease regardless of the participants' medical treatment status. Participants radically adapt their everyday life by, for instance, choosing different clothes, rarely going on vacation as well as reducing social and physical activities. Furthermore, they reported stress to be the most relevant aggravating factor for their disease. These findings are in accordance with other large studies in the USA and Europe [24, 28].

Concerning the utilization of medical care for psoriasis, almost half of the study participants did not undergo treatment for their skin condition at the time of the survey. Although the online design of the study could lead to an overestimation of this untreated subgroup, similar results have been shown before for dermatological care in the German state of Bavaria [18]. Together with the fact that the study population displayed a moderate disease severity (mean BSA  $6.1 \% \pm 8.0 \%$ ), the findings are suggestive of the existence of insufficient person-centered medical care.

With regard to the medical professionals being consulted by the study population currently in treatment, dermatologists were most frequently visited, followed by general practitioners. Only a minority consulted a specialized center, which interestingly generates the highest proportion of successful treatments. Looking at the medication used, most participants use prescribed topical preparations and around 50 % have experiences with a systemic medication. This latter proportion is about 10 % lower than shown in a large German national study (PsoHealth3) [29], but may reveal the reality of the situation, due to the person-based and not patient-based approach. Nevertheless, satisfaction with the current treatment is relatively low. About 60 % of the participants in medical care are not at all, not or only moderately satisfied. Individuals who receive systemic treatment were more likely to be satisfied than individuals without, reflecting the known success of these medications [30]. The main reasons reported for dissatisfaction with the medication are lack of effectiveness and side effects. However, if applied correctly, topical therapeutic options are very safe and successful [31]. In addition, a great number of biologics as well as small molecules display highly effective and relatively safe systemic treatment options [4]. Possible reasons for not consulting physicians were "too little time" as well as the impression of "too little interest" shown by the physician.

The presented study was conducted as an online survey. The main limitations of online studies opposed to paper studies are low response rates and participation biases. Typically, males, natives, higher educated and younger people respond more frequently than females, immigrants, lower educated and elder people [32, 33]. People without internet access or digital literacy are excluded from the outset [34]. This survey was only accessible to regular users of Facebook/Google and used personalized advertisements. Therefore, a selection bias towards younger people and towards people that had already visited psoriasis-related websites, is present. Concerning the latter aspect, it has to be taken into account that people who are dissatisfied with their medical care are more prone to search online for information and therefore are more likely to discover and participate in online studies. Consequently, the percentages of individuals with psoriasis not being treated or unsatisfied may be overrated. In addition, diagnosis of psoriasis was only self-reported and not verified by, for example, medical records and/or physicians, leading to the possibility of erroneously including participants with other/no dermatological diseases. Nevertheless, online surveys are a suitable tool for recruiting unique populations [35]. In this study not only people who are, but also those who are not in professional medical care for their psoriasis, are reached. Furthermore, in the past years the concept of person-centered, instead of patient-centered, has been implemented as one way to analyze and later meet people's health care needs.

Person-centeredness deepens the understanding of “the whole person” as opposed to visit-based, disease-centered care. An anonymous online survey not primarily aiming to evaluate specific treatments, but rather to find overall reasons for (dis-)satisfaction provides useful information for person-centered care in the future [36, 37].

In summary, the online study data obtained suggests an under-treatment of people that suffer from psoriasis. Moreover, it successfully identified reasons for dissatisfaction in currently treated individuals and reasons for not consulting physicians in not treated, but equally affected people. The German health care system provides accessible, safe and efficient medication, but apparently cannot address every affected patient. Here educational programs, as they exist for other chronic diseases such as diabetes, could be a possible solution [38]. Ideally, these would be provided online in order to reach the newly identified target population, which is often not in direct contact with the health care system.

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## Conflict of interest

ACP received financial support for one conference from Novartis. NW received honoraria for lectures and advisory board participation from Novartis. MR, KR, EH and DB are employees of Novartis.

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