Appendix S1

Patient characteristics

The patient questionnaire contained questions on socioeconomic characteristics like age (in years), gender (male or female), employment status (currently having a job or not), lifestyle habits like smoking (yes/no) and drinking alcohol (range from 0 = never to 4 = daily). In the physician questionnaire the clinicians were asked to state the body weight and height of the patients (open text response, subsequent calculation of the body mass index, BMI),

Disease burden

Patients were asked on HRQoL impairments by means of the Dermatology Life Quality Index (DLQI). This is based on 10 questions, each is scored from 0 to 3, resulting in a range from 0 (no HRQoL impairments) to 30 (maximum HRQoL impairments) (26). The impact of PSO on different career related aspects (career choice, job search, keeping the job and career development) was rated by the patients on five 5 point Likert scales (0=not at all to 5=completely influenced by the disease).

The physician questionnaire included an assessment of the PSO severity by means of the PSO Area and Severity Index, PASI (range from 0 = no severity to 72 = maximum severity) (28) and body surface area (BSA) assessment (free text response on the percentage of body surface with skin lesions).

Medical treatment and its barriers

The dermatologists were asked on the current treatment (multiple choice and free text response).

Furthermore, patients were asked on the actual waiting times for their appointment with the dermatologist (single choice from a list of possible waiting times), the actual distance travelled to the dermatology practice (free text response), the maximum waiting time and the maximum distance they would (theoretically) be willing to travel for an appointment with a PSO specialist (free text response). Also we asked for experiences with non-medical support like psychotherapy (yes/no) and patient education classes (yes/no).

Patients were also asked for experiences with the disease and the treatment in the past in order to draw a patient journey through PSO care. The questions in this complex referred to years since first symptoms, years since first diagnosis, PSO severity at first diagnosis, first consulted specialist, first treatment and number of treatment changes. Answers could be given as single choices from a list and free text response options.

Treatment-related burden and treatment satisfaction

Treatment related burden was measured using items from the “therapy” domain of the Freiburg Life Quality Assessment for patients with a chronic skin disease (FLQA-d)(27). Patients were asked to answer on a five point

Likert scale how much they agree to the statement “The treatment is a burden to me” (scale from 0=“not at all” to 4=“completely agree”). Also they should state how long they need for their daily treatment (single choice from a list between “no time” to “>60 minutes”). Dissatisfaction with treatment was assessed by the categorial variable “How satisfied have you been with the treatment of your psoriasis over the past 12 months?” (Scale from 1 = very satisfied to 4 = very dissatisfied).

Appendix S2

Implications for future research

Future health services research should include factors of treatment access and the framework of healthcare systems when comparing the quality of healthcare in psoriasis[1]. Second, measures for overcoming barriers to guideline-compliant care as promoted by the WHO in its Global Report (26) should be based on research data for greater precision and sustainability. Research on access to care should also include social determinants such as socio-economic status, geographical background and ethnicity. Since studies in the US in particular found significant differences in how psoriasis presents and impacts the quality of life in non-White individuals[2], data on ethnic origin would make sense in order to be able to address this more specifically in the European context.

Implications for practice

For daily practice it is important to know that access to guideline-compliant treatments and consecutive improvements in clinical scores are associated with gains in health-related quality of life. Early use of the most adequate treatment provides optimized patient benefits in healthcare for psoriasis. With respect to the health policy, stakeholders can learn that lack of access to healthcare can deteriorate not only the skin conditions in psoriasis but also the patients´ wellbeing and quality of life. Comparison between countries may enforce the communication with decision makers and provide “best practice” examples of health care as promoted by WHO in its global report (26).

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[1] Eissing L, Radtke MA, Zander N, Augustin M. Barriers to guideline-compliant psoriasis care: analyses and concepts. J Eur Acad Dermatol Venereol 2016; 30: 569–575.

[2] Lytvyn Y, Sachdeva M, Mufti A, Yeung J. Dermatology: how to manage psoriasis and recognize differences in pathophysiology and presentation in patients with skin of colour. Drugs Context 2022; 11: 2021-9-3.