JA, ICH HABE MEINE VITILIGO AKZEPTIERT. SCHLIESSLICH HABE ICH KEINE WAHL.

65 % aller Menschen mit Vitiligo wird gesagt, ihre Erkrankung sei nicht behandelbar.[1] Noch gravierender ist, dass nahezu die Hälfte aller Betroffenen eine Behandlung überhaupt nicht mehr in Betracht zieht.[1] Wie Sie wissen, tritt Vitiligo meist im Teenageralter auf – und ohne zugelassene Therapie fühlen sich viele Betroffene in einem Zustand der Ungewissheit gefangen. Deshalb forschen wir an neuen wissenschaftlichen Ansätzen. Denn wenn wir uns alle mehr mit der Erkrankung Vitiligo befassen, haben Ihre Patientinnen und Patienten eines Tages vielleicht wieder eine Wahl.

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The 'Chronic Itch Burden Scale': giving patients with chronic pruritus a voice

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Linked Article: Theunis *et al.* Br J Dermatol 2022; **186**:86–95.

More than a quarter of all people experience the burden of chronic pruritus (CP) during their lives.[1] Undoubtedly, CP negatively affects patients' health-related quality of life (HRQoL).[2] It may be perceived as disturbing during everyday activities, when sleeping and it may also affect how the patient is feeling. With various levels of severity, CP has more or less burdensome consequences for the patients and their functioning. For some individuals, scratching their skin is also embarrassing (itch–scratch cycle).

As CP and its impact on HRQoL are a subjective experience, only patients themselves can describe their symptoms and how they are affected. Therefore, patient-reported outcome measures (PROMs) should be used in order to evaluate completely the severity of CP and its impact on HRQoL from the patient's perspective. Unfortunately, so far, there are few PROMs that assess the severity of CP and its impact on HRQoL.[3–5] Furthermore, these existing instruments were not necessarily developed following international guidelines.[6]

In this issue of the *BJD*, Theunis *et al.* present a newly developed instrument to fill this gap: the Chronic Itch Burden (CIB) scale.[7] Addressing the severity of CP together with its impact on HRQoL comprehensively, this approach and the resulting instrument is novel. According to international guidelines, the development of a PROM has to be patient oriented.[8] Theunis *et al.* have implemented this and involved many patients in the instrument's development. A conceptual framework was built. Domains and subdomains of CP severity and impact were identified. Cognitive debriefing interviews with affected patients were conducted to assess comprehensibility, comprehensiveness and relevance of the single items according to the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) criteria.[9] Modern psychometric analyses were performed to investigate measurement properties of the CIB scale.

The study was limited to a single pool of individuals from France. Despite this, a large sample size of 300 individuals was achieved. Further validations of this new instrument in other languages using large samples of patients with CP should be aimed for. Furthermore, future studies should consider the evaluation of further measurement properties of the CIB scale, such as test–retest reliability or the ability to detect change over time. Nevertheless, this comprehensive measure performed well in its initial validation and can therefore be used in clinical research to measure the severity and impact on HRQoL in patients with CP.

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The critical need for patient-reported outcome measures to assess the severity and impact of systemic sclerosis

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Hand involvement is almost universal in patients with systemic sclerosis (SSc) and a major cause of pain and disability. The aetiology of hand involvement in SSc reflects the complexity of the disease and is often multifactorial. This includes progressive skin fibrosis, joint contractures, musculoskeletal disease (e.g. inflammatory arthritis and myositis), vasculopathy (e.g. Raynaud phenomenon and digital ulcers) and subcutaneous calcinosis.[1–3] There is also broad-ranging emotional impact, including patients' concerns about the physical appearance of their hands.

Patient-reported outcome measures (PROMs) provide valuable insights into the patients' perspectives of their disease. In SSc, PROMs are widely used in clinical practice and trials, including a number of SSc-specific instruments. However, a key issue for discernibility is that patients with SSc were largely not involved in the development of the majority of these instruments.[4] This is of key importance because PROMs should capture the multifaceted impact and severity of disease, and regulators require evidence of this to support drug labelling claims.[5] For example, the U.S. Food and Drug Administration requires a demonstration of clinical benefit (e.g. by feel, function and survival endpoints) for product approval.

In this issue of the BJD, Sibeoni *et al.* report the development of an SSc PROM: the Hand scleroderma lived Experience (HAnDE) scale.[6] The authors used a sequential mixed-methods approach. The first phase was an inductive process to understand the lived experience of patients, in order to generate a provisional 18-item scale. The second phase assessed the psychometric properties of the scale to validate the PROM, including reducing it to 16 items. The internal consistency of the scale was excellent. Construct validity was very good, including concurrent validity, which showed significant correlations with a number of widely used PROMs in SSc.

The HAnDE PROM was developed through a comprehensive approach, including understanding the lived patient experience. However, there are a number of aspects to consider. The study was conducted in a single country (France) and patients were recruited from specialist centres, which could limit the generalizability of the PROM for patients with milder hand involvement not requiring speciality services. The authors highlight that although the number of patients in phase two could appear small ($n = 105$), no consensus exists on the minimum number required for principle component analysis.[6] There were also differences in patient characteristics between the two phases, which could be important (e.g. the prevalence of active digital ulcers and calcinosis).

The HAnDE is a welcomed PROM to assess the overall impact of hand involvement in SSc. The PROM captures the broad-ranging impact of SSc and mirrors recent qualitative work undertaken to understand the patient experience of SSc digital vasculopathy.[7–9] This includes physical symptoms; impairment of physical and social activity; emotional impact, including personal relationships; and the impact of treatment. Of note, hand involvement has been reported to be a limitation to completion of PROMs in SSc.[10] Future research is warranted to further develop this comprehensive PROM for use in clinical practice and trials, including sensitivity to change, to assess the impact of treatment interventions prescribed by rheumatologists and occupational therapists, and adaption for other languages.

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