Pictorial Representation of Illness and Self Measure (PRISM)

A Novel Visual Instrument to Measure Quality of Life in Dermatological Inpatients

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**Objectives:** To validate the PRISM (Pictorial Representation of Illness and Self Measure) tool, a novel visual instrument, for the assessment of health-related quality of life in dermatological inpatients compared with the Dermatology Life Quality Index (DLQI) and the Skindex-29 questionnaires and to report qualitative information on PRISM.

**Design:** In an open longitudinal study, PRISM and Skindex-29 and DLQI questionnaires were completed and HRQOL measurements compared.

**Setting:** Academic dermatological inpatient ward.

**Participants:** The study population comprised 227 sequential dermatological inpatients on admission.

**Intervention:** Patients completed the PRISM tool and the Skindex-29 and DLQI questionnaires at admission and discharge.

**Main Outcome Measures:** PRISM Self-Illness Separation (SIS) score; Skindex-29 and DLQI scores; and qualitative PRISM information by Mayring inductive qualitative context analysis.

**Results:** The PRISM scores correlated well with those from the Skindex-29 (r=0.426; P<.001) and DLQI (r=0.304; P<.001) questionnaires. Between PRISM and Skindex-29 scores, the highest correlations were for dermatitis (r=0.614) and leg ulcer (r=0.554), and between PRISM and DLQI scores, the highest correlations were for psoriasis (r=0.418) and tumor (r=0.399). The PRISM tool showed comparable or higher sensitivity than quality of life questionnaires to assess changes in the burden of suffering during hospitalization. Inductive qualitative context analysis revealed impairment of adjustment and self-image as major aspects. Patients overall expected symptomatic and functional improvement. In patients with psoriasis and leg ulcers, many expected no treatment benefit.

**Conclusions:** The PRISM tool proved to be convenient and reliable for health-related quality of life assessment, applicable for a wide range of skin diseases, and correlated with DLQI and Skindex-29 scores. With the PRISM tool, free-text answers allow for the assessment of individual information and potentially customized therapeutic approaches.

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Particularly with skin diseases, objective disease parameters such as extent, thickness, and color insufficiently reflect the burden of disease as perceived by affected patients. Increasing the patient’s health-related quality of life (HRQOL) is a generally accepted therapeutic aim in dermatological practice.

Instruments developed in other disciplines are inadequate to assess HRQOL in dermatology; therefore, skin-specific questionnaires such as the Dermatological Life Quality Index (DLQI) and the Skindex-29 have been developed and validated. These self-report HRQOL questionnaires, which validly and sensitively assess appearance, itch, and functional impairment, have gained clinical acceptance and are regularly used in clinical trials.

These questionnaires have limitations. Because they were developed to assess inflammatory skin diseases, they perform best in this limited scope of skin disease. Standardized questions intended to apply to a range of conditions often do not address disease-specific concerns. Repeated assessments tend to exhaust the patient’s willingness to complete the questionnaires, a phenomenon known as respondent burden. Computation of HRQOL score from questionnaires is cumbersome and not intuitive for the clini-
cient. Written qualitative questionnaires may be limited to relevant use within the cultural region for which they were developed. Most notably, these questionnaires work with set questions, in which the answers contribute to the total score but yield little information about the particular individual’s main concern and specific needs.

Recently, PRISM (Pictorial Representation of Illness and Self Measure), a novel visual instrument to assess the global illness impact, has been successfully validated for several chronic diseases including rheumatoid arthritis, chronic obstructive pulmonary disease, and systemic lupus erythematosus. Data and clinical experience with this instrument indicate that it is not only easy to use but can be used by practicing clinicians to assess therapeutic effect as well as to individualize treatment goals. Beyond the dimension of HRQOL assessment, the PRISM tool offers specific information that may be used to tailor treatment to individual needs.

As a first step toward clinical use of the PRISM tool in skin diseases, we sought to validate PRISM as an HRQOL assessment tool in dermatological inpatients compared with the well-established and validated DLQI and Skindex-29 HRQOL questionnaires. We were further able to assess the burden of illness in these patients by analyzing their plain-text answers to PRISM questions, using the Mayring inductive qualitative context analysis.

METHODS

PATIENTS

Following approval by the institutional review board of the Canton of Zürich, Zürich, Switzerland, we asked all patients admitted consecutively to our dermatological inpatient ward from July 2005 to July 2006 for a projected stay of at least 7 days to participate in the study. Patients with severe dementia, blindness, deafness or inability to communicate in the local language were excluded. Following written informed consent, all enrolled patients completed the PRISM4,6,8 task with the investigators (B.M. or S.S.) at the following time points: at admission, once every week throughout their inpatient stay, and finally at discharge. At the same time points, patients filled in the German versions of the validated dermatological HRQOL questionnaires, the Dermatology Life Quality Index (DLQI) and Skindex-29.9

THE PRISM TOOL

We presented the PRISM tool as described4,6,8 and illustrated in Figure 1. Patients were shown a white A4-sized metal board with a yellow circle (diameter, 6 cm) at the bottom right-hand corner. Each patient was asked to imagine that the plate represented his or her life at this moment in time, with the circle representing his or her “self.” Patientes were then handed a red circular disk (diameter, 4 cm). They were asked to imagine that the red disk represented their illness and were asked “Where would you put the illness in your life at this moment?” The main outcome measure was the distance between the yellow circle and the red disk, called the Self-Illness Separation (SIS) distance, measured between the centers of the circles and ranging from 0 to 270 mm. Higher SIS distances corresponded to lesser perceived impairment. In addition, patients were asked to explain in their own words why they put the red disk at that specific position and what the chosen SIS distance meant to them.

VALIDATION OF THE PRISM TASK

As a first step, we assessed correlation between PRISM SIS scores and the Skindex-29 and DLQI scores using the Spearman rank correlation coefficient (p). We also assessed correlation among the 3 instruments for each single point in time when all 3 were administered.

As a second step, we assessed each instrument’s sensitivity to change during the course of inpatient stay as expressed by differences in mean percentages of that instrument between admission and discharge. Sensitivity to change was also expressed by Cohen effect size (d)16 (difference in the mean values between admission and discharge divided by the mean [SD]
RELIABILITY OF DLQI AND SKINDEX-29

To assess the internal consistency of the 2 HRQOL questionnaires in our cohort, we used Cronbach α. We performed statistical analyses for all patients together as well as for the “dermatitis,” “psoriasis,” “leg ulcer,” and “skin tumor” diagnosis subgroups using SPSS for Windows 11.5 (SPSS Inc, Chicago, Illinois) and Microsoft Excel 2000 (Microsoft Corp, Redmond, Washington).

QUALITATIVE PRISM DATA ANALYSIS

We transcribed the patients’ spoken explanations verbatim for both PRISM SIS scores and treatment expectations and analyzed them according to the method of inductive qualitative context analysis described by Mayring.7 We then assigned these responses to different subcategories, specifically to 4 response categories describing the significance of the PRISM SIS score (symptom intensity, adjustment, self-image, and handicap) and into 3 response categories describing treatment expectations (symptom reduction, less handicap, and no treatment expectations). After being assigned to these various categories, the responses were independently rated by 2 raters to test reliability. The correlation between the findings of these 2 raters was calculated by Cohen κ.17 The 4 PRISM-related response categories had a correlation of κ = 0.95, while the 3 treatment expectations categories showed a correlation of κ = 0.91. These results indicated high interrater agreement on both measures and high reliability of categorizing individual responses into more general terms.

RESULTS

PATIENTS

Of 227 admitted inpatients, 186 completed the PRISM task on admission. Forty-one patients (18%) could not be enrolled because of dementia (n = 21 [9%]), linguistic problems (n = 9 [4%]), or blindness or deafness (n = 2 [1%]). Figure 2 shows the number of enrolled patients who completed the PRISM, DLQI, and Skindex-29 questionnaires, as well as follow-up evaluations for each of these measures, exclusions from the study, and number lost to follow-up. Most patients lost to follow-up were discharged before completing 1 week of hospitalization and therefore were not assessed a second time. Patient characteristics and diagnoses are provided in Table 1. Other diagnoses (n = 56 [30%]) comprised cutaneous eruptions from drug use, hypodermatitis, prurigo, urticaria, vasculitis, acne inverse, dyskeratosis follicularis, dermato(myositis, and lichen sclerosus et atrophicans.

RELIABILITY OF SKINDEX-29 AND DLQI

Both HRQOL measures showed a high degree of internal consistency as expressed by Cronbach α, both overall and in several subscores (DLQI, α = 0.88; Skindex-29 global score, α = 0.96; symptoms subscore, α = 0.85; social functioning subscore, α = 0.93; and emotions subscore, α = 0.91). This suggests that both were equally effective at capturing patient responses.

VALIDITY

Overall, PRISM scores correlated well with Skindex-29 and DLQI scores (ρ = 0.426 and 0.304, respectively [P < .001 for both]). When considered by subgroup, the highest correlations between PRISM and Skindex-29 scores were observed in patients with dermatitis or leg ulcer (ρ = 0.614 [P < .001] and 0.554 [P = .003], respectively). The highest correlations between PRISM and DLQI scores were found in patients with psoriasis or tumor (ρ = 0.418 [P < .01] and 0.399 [P = .04], respectively) (Table 2).

Table 1. Patient Characteristics

<table>
<thead>
<tr>
<th>Patient Characteristic</th>
<th>Total (N=186)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, y</td>
<td>64.6</td>
</tr>
<tr>
<td>Quartile range</td>
<td>45.3–76.2</td>
</tr>
<tr>
<td>Min/max</td>
<td>16.5/92.1</td>
</tr>
<tr>
<td>Duration of inpatient stay, mean (SD), d</td>
<td>17.4 (13.4)</td>
</tr>
<tr>
<td>Sex, male, No. (%)</td>
<td>94 (51)</td>
</tr>
<tr>
<td>Swiss nationality, No. (%)</td>
<td>156 (80)</td>
</tr>
<tr>
<td>Marriage status, No. (%)</td>
<td></td>
</tr>
<tr>
<td>Unmarried</td>
<td>37 (20)</td>
</tr>
<tr>
<td>Married</td>
<td>149 (80)</td>
</tr>
<tr>
<td>Divorced</td>
<td>31 (21)</td>
</tr>
<tr>
<td>Widowed</td>
<td>21 (14)</td>
</tr>
<tr>
<td>Family, No. (%)</td>
<td></td>
</tr>
<tr>
<td>With</td>
<td>109 (59)</td>
</tr>
<tr>
<td>Without</td>
<td>89 (41)</td>
</tr>
<tr>
<td>Diagnoses, No. (%)</td>
<td></td>
</tr>
<tr>
<td>Dermatitis</td>
<td>55 (30)</td>
</tr>
<tr>
<td>Tumor</td>
<td>36 (19)</td>
</tr>
<tr>
<td>Leg ulcer</td>
<td>20 (11)</td>
</tr>
<tr>
<td>Psoriasis</td>
<td>19 (10)</td>
</tr>
<tr>
<td>Other</td>
<td>56 (30)</td>
</tr>
</tbody>
</table>

Abbreviations: Min/max, minimum/maximum.
SENSITIVITY TO CHANGE

All 3 instruments showed a significant reduction in the patients’ burden of illness during hospitalization ($P < .001$, Wilcoxon signed-rank test) (Figure 2). For patients overall, PRISM showed the highest sensitivity to change between admission and discharge as expressed by Cohen effect size, with PRISM showing an effect size of $d = 0.67$ compared with $d = 0.59$ for Skindex-29 and $d = 0.54$ for DLQI. In the leg ulcer, psoriasis, and tumor diagnosis subgroups, PRISM again showed the highest effect size of the 3 instruments. In patients with dermatitis, by contrast, the HRQOL questionnaires showed a higher effect size than PRISM (Figure 3 and Table 3).

QUALITATIVE ASPECTS OF BURDEN OF ILLNESS

Patients who were asked at admission about such qualitative measures as their treatment expectations and fears answered in terms that suggested patterns by diagnosis group. Patients with leg ulcer mainly hoped to achieve symptom reduction. Patients with dermatitis most frequently expected a reduction in handicap. Among patients with psoriasis, a striking 28% (6 patients) did not express any expectations. Patients’ primary negative expectations also varied according to diagnosis. Patients with psoriasis and leg ulcer were most likely to fear self-image impairment. Patients with tumor most frequently reported concerns about adjustment. Qualitative content analysis according to Mayring’ was reliable, as indicated by the very small interrater (S.B. and J.J.) variability (percentage of overall agreement, 96.1% [κ = 0.948; $P < .001$], data not shown). Table 4 gives the patient answers as assigned to categories for dimensions of suffering and treatment expectations, with sample responses.

COMMENT

The aim of this study was to validate the PRISM tool for assessment of HRQOL in dermatologic inpatients. Reliability of the HRQOL questionnaires in our cohort was high, as expressed by Cronbach $\alpha$ (Table 3). Correla-

![Figure 3. Reduction in Mean Burden of Illness During Hospitalization. Mean percentages of sum scores of PRISM (Pictorial Representation of Illness and Self Measure), Skindex-29, and Dermatology Life Quality Index (DLQI) during hospitalization among 110 patients. PRISM Self-Illness Separation (SIS) score is displayed as $1 - \text{SIS}$ to facilitate comparison with Skindex-29 and DLQI. From admission to discharge, PRISM (1–SIS) decreased by 17.6% ($P < .001$), and Skindex-29 and DLQI sum scores decreased by 11.7% ($P < .001$) and 13.7% ($P < .001$) respectively. *$P < .001$.](http://archderm.jamanetwork.com/pdfaccess.ashx?url=/data/journals/derm/5211/ on 06/19/2017)
Study 36-Item Short-Form Health Survey (SF-36) subscores ranged from $p = 0.177$ to 0.392—notably lower than the comparable correlations for the questionnaires in our study, potentially because of a wider range of disease conditions included. The correlation between PRISM and Hospital Anxiety and Depression (HADS) depression scale in the same cohort was similarly low at $p = 0.312$. The correlation of the 3 instruments used in our study was thus higher than to be expected from previous studies in other disease conditions.

All 3 instruments we used proved capable of significantly detecting improvement in HRQOL during hospitalization. In measuring overall changes in inpatient HRQOL, the PRISM tool performed equally as well as the self-administered questionnaires. In measuring effect size, PRISM was the most sensitive tool, both across all groups and in most diagnosis subgroups. An additional advantage of the PRISM tool is its ability to bridge cross-cultural differences. While such differences exist for all HRQOL questionnaires, PRISM may be the least influenced by cultural differences because it uses a more global, intuitive, and graphic—indeed, pictorial—assessment of HRQOL.

In a recent study by Reimus et al, patients with psoriasis were offered the original PRISM board with the key difference of variable-sized illness disks. By offering patients the additional factor of expressing the impact of illness by changing disk size, the study extracted meaning from the distance measure SIS. In 59 patients with psoriasis, the study by Reimus et al showed little correlation between the Psoriasis Area and Severity Index (PASI) and PRISM ($p = 0.14$) on the one hand and between PASI and the Health Monitor Questionnaire scores (0.10-0.16) on the other, offering further evidence that the changeable disk size reduced the significance of the distance measure SIS. We therefore do not recommend the use of this revised version of PRISM.

An additional challenge to HRQOL assessments, one that has been reported before, is the often limited association between physical findings as reported by the physician and subjective quality of life issues as reported by the patient. Considering this stumbling block to the possibility of ever finding a gold standard for quality of life assessments, we can at least conclude that the 3 instruments in our study correlated well with one another, and all seem potentially useful for HRQOL assessment in dermatological inpatients.
The PRISM tool offers particular insight into a patient’s experience of chronic skin disease by soliciting spoken answers, which when analyzed by the inductive qualitative context described by Mayring’s showed impairment of adjustment and self-image to be major aspects of suffering. The free-text results further revealed significant trends by diagnosis group. Patients with tumor mainly suffer from adjustment problems; patients with psoriasis or leg ulcer, mainly from self-image impairment; and patients with dermatitis, from both in equal proportions. Our results showed symptom intensity and handicap to be relatively minor aspects of suffering in chronic skin diseases, distributed equally among the different diagnoses. The PRISM tool also reveals trends in treatment expectation. All patients reported symptom reduction as a primary expectation of therapy. Patients with dermatitis or tumor further reported a strong expectation of handicap reduction. The majority of patients with psoriasis or leg ulcer shared the general expectation for symptom reduction, but the second most frequent answer among these patients was a complete lack of expectations. This expressed lack of expectation may be due to the chronic and relapsing nature of these disease conditions. The qualitative analysis of answers made possible by PRISM can thus help clinicians treat patients as individuals, customizing treatment to each patient’s diagnosis as well as particular expressions of suffering and expectations.

Additional strengths of the PRISM tool in our study included the completeness of data it yielded, made possible by its interview format. Patients in our study left a sizable 32% of Skindex-29 questionnaires incomplete, leading to considerable exclusion from analysis or imputation. The specific items patients chose to skip in Skindex-29 all concerned sexuality and social impairment and isolation (question numbers 4, 8, 14, 20, 22, 24, 25, 26, and 29), potentially useful measures of the burden of illness. The DLQI offered more data than this, with only 2% of all questionnaires containing missing items, but still less than PRISM. Furthermore, because PRISM can be completed in the patient’s own words, it offers data independent of the patient’s linguistic skills and education. As a final advantage, PRISM takes an experienced interviewer only 5 minutes to complete.

Weaknesses of the PRISM tool include its dependence on an interviewer, which precludes patients from filling out questionnaires anonymously and in private. This may result in inhibitions in answering sensitive but potentially relevant questions. There is also a considerable time burden on interviewers, particularly with repeated interviews, but this may be relieved by paper PRISM forms, which have been used,24 and an online PRISM tool, which is currently under development.

In conclusion, we found PRISM to be an able tool for capturing changes in HRQOL in our dermatological patients, keeping stride with established questionnaires. It offered the additional advantages of measuring a more global self-assessment of the patient’s disease than HRQOL questionnaires, capturing patients’ treatment expectations more specifically and minimizing differences of culture and education by using a graphic, intuitive approach. Because of these features, PRISM should be added to the standard toolbox of HRQOL measurement. A qualitative analysis of PRISM answers offers promise, even beyond HRQOL assessment, for an even more customized treatment of chronic skin diseases in the future.

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REFERENCES

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