Health-related quality of life in dermatology: measurement, interpretation and application
Prinsen, C.A.C.

Citation for published version (APA):

General rights
It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations
If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: http://uba.uva.nl/en/contact, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.
Health-related quality of life assessment in dermatologic practice: relevance and application

4.1

OD van Cranenburgh, CAC Prinsen, MAG Sprangers, Phl Spuls, J de Korte

*In alphabetical order; both authors contributed equally to this paper

Dematol Clin 2012; 30(2):323-32
The following is a brief summary of important points and objectives for recall:

• Health-related quality of life (HRQoL) data of patients may be used for various purposes: (1) to increase a patient’s self-awareness and empowerment, (2) to increase patient-centeredness in health care, (3) to make an optimal choice for treatment, (4) to monitor treatment over time and determine treatment effectiveness, and (5) to improve treatment outcome.

• HRQoL assessment is particularly relevant for patients with chronic skin diseases that are known to have substantial and enduring adverse effects on HRQoL.

• Many HRQoL questionnaires are currently available. The selection of a HRQoL questionnaire will depend on several factors, such as the functions it has to fulfill in clinical practice, the specific patient population, the psychometric characteristics of a specific questionnaire, and the local policy and conditions.

• We have chosen the Skindex-29 as the questionnaire of first choice to be used in dermatology.

• An electronic assessment may facilitate the application of HRQoL in dermatologic practice.

• To use HRQoL data in clinical practice, scores should be interpreted promptly and accurately. Information on the interpretation of Skindex-29 scores is currently available.

• In discussing HRQoL scores, it is important not to focus on the overall score of the Skindex-29, but on the 3 domain scores.
INTRODUCTION

Patient-reported outcomes (PROs) are reports or assessments of any aspect of a patient's health status or impact of treatment that come directly from the patient, without the interpretation of the responses by anyone else. Regulatory agencies in many countries take patient-relevant criteria into consideration in decisions on reimbursement of new therapies, resulting in an increased importance of PROs in clinical trials. The application of PROs in clinical practice is growing as well. Assessment of PROs, such as patients’ experienced disease severity, health-related quality of life (HRQoL), treatment adherence, and treatment satisfaction, appears to have added value for daily clinical practice.

In a systematic review of studies on the impact of PRO assessment in clinical practice, Valderas and colleagues stated that (1) PRO assessment can be time consuming, (2) both patients and physicians may perceive PRO questionnaires as burdensome, (3) the interpretation of PRO scores in a clinically meaningful manner requires additional resources, and (4) the implications for treatment are not apparent. On the other hand, PRO assessment can also have a positive impact on clinical practice, specifically by improving the diagnosis and recognition of problems, and in patient–physician communication. The investigators also pointed out that studies included in their review were heterogeneous and of an inferior methodological quality and that, as a result, no evident conclusion could be drawn with regard to the effect of PRO assessment in clinical practice.

An important PRO in health care is HRQoL. HRQoL reflects patients’ evaluation of the impact of disease and treatment on their physical, psychological, and social functioning and well-being. Chronic skin diseases, such as acne, eczema, hidradenitis suppurativa, psoriasis, and vitiligo, have been found to adversely affect patients’ HRQoL. In many patients, this impact is profound. In such chronic skin diseases, dermatologic treatment can offer a temporary suppression and/or remission of severity and symptoms. As a result, many patients have to cope with the burden of their skin disease for years, or even throughout their entire lives. Patients often consider improvement of HRQoL as an important treatment goal; hence, dermatologic treatment should aim to decrease disease severity and to increase patients’ HRQoL.

HRQoL is gradually becoming a standard outcome parameter in clinical studies and health care management. Because the major goal of therapeutic interventions is to make patients feel better, HRQoL assessment is likely to become even more important in the future. Because of this development, the quality of HRQoL assessment itself, correct management and interpretation of HRQoL data, and the communication of such data with the patient, deserve attention.

HRQoL is generally measured with reliable and valid self-reported instruments (i.e., questionnaires). The application of such questionnaires in daily clinical practice may improve evidence-based practice, facilitate communication with the patient, and, herewith, the process of shared decision making between patients and physicians. In a randomized controlled trial (RCT) in the field of oncology, HRQoL assessment resulted in a significant increase of relevant information on and discussion of chronic symptoms; moreover, the explicit use of HRQoL information during patients’ consultation was associated with a significant improvement in patients’ well-being. Another RCT indicated that HRQoL assessment in
daily clinical oncology practice facilitates the discussion of HRQoL issues and heightens physicians’ awareness of their patient’s HRQoL. 10 Nevertheless, the application of HRQoL assessment is not customary in dermatologic practice and there are several practical and attitudinal barriers. A deeper understanding of the benefits of HRQoL assessment for both dermatologists and patients may improve its application. Hence, members of a Dutch expertise center on HRQoL in dermatology took the initiative to start a working group, consisting of 10 dermatologists, a psychologist, and a clinical epidemiologist, on HRQoL assessment in clinical practice. This working group produced a guideline to support the application of HRQoL assessment in routine dermatologic practice. 11 In this article, and following this guideline, we attempt to provide answers to the 3 questions: (1) What is the relevance of HRQoL assessment to dermatologic practice? (2) Which patients would benefit most from routine HRQoL assessment? (3) How can HRQoL assessment be applied in clinical practice? In answering these questions, we aim to contribute to the discussion on and the implementation of HRQoL assessment in routine dermatological practice.

**HRQOL ASSESSMENT IN DERMATOLOGY: WHY?**

**Patients’ self-awareness and empowerment**

By filling out an HRQoL questionnaire and communicating about the answers to the questions, patients may gain more insight into the impact of the skin disease on their own physical, psychological, and social functioning and well-being. Most likely, this insight will increase patients’ self-awareness; for instance, awareness of specific psychological problems and of specific health care needs. Such awareness, and the acknowledgement of needs by the dermatologist, may further empower patients to share and discuss their problems with significant others, such as a partner, relatives and friends. 12-14

**Patient-centered health care**

Clinical evaluations of the severity of a skin disease are not highly correlated with patients’ perceptions of HRQoL. 15,16 Consequently, HRQoL assessment is of particular importance to enable the dermatologist to grasp the impact of the skin disease and/or its treatment on an individual patient. 17 In addition, such data may highlight specific aspects of HRQoL that are affected the most, for instance shame or depression. In patients with a chronic skin disease, this information might be of relevance, particularly because of a relatively high prevalence of psychosocial problems, often hidden “under the skin”. 17,18 Furthermore, insight into these problems creates an opportunity to communicate in an empathic and responsive way, thereby supporting patients in coping with their problems more effectively. Communication about HRQoL may also be helpful in engaging patients in a discussion on treatment preferences to allow mutual or shared decision making.

**An optimal choice of treatment**

HRQoL data, in addition to clinical information, contribute to a more comprehensive insight into a patient’s situation after diagnosis and before to the choice for a specific treatment. By including HRQoL data into the decision-making process, the dermatologist and the patient can
make an optimal, shared choice for a specific treatment in terms of its setting (e.g., inpatient, outpatient, day care, specialty care), intensity or invasiveness, position in the conceivable order of treatments over time, and/or combinations with other treatments. For instance, if a patient experiences a high level of symptomatic burden, a more intensive or invasive treatment can be considered. A better-tailored treatment is expected to be better tolerated and adhered to by the patient. Additionally, feasible aims of a specific treatment can be discussed using HRQoL data; for instance, a reduction of itch, a decrease in or clearance of visible lesions, or a reduction in the degree of disease severity within a specific time frame.

Furthermore, patients’ needs for additional care, as a supplement to regular dermatologic care, can be identified and addressed. Some patients may experience low levels of HRQoL that cannot be explained by disease severity only. Other patients may have serious problems with respect to specific domains or aspects of HRQoL, such as suffering from depression, feeling socially isolated, or encountering problems at work. In such instances, referral to a social worker, a psychologist, or a psychiatrist might be indicated, and can result in a valuable adjuvant therapy.

**Monitor treatment over time and determine treatment effectiveness**

HRQoL scores of a patient before treatment may be compared with scores at follow-up visits. In this way, the treatment process can be monitored over time. HRQoL data obtained at follow-up visits may also be helpful in checking negative consequences or side effects of treatments; for instance, an increase of itch, pain, irritation, tiredness, sleep, or depression. Such HRQoL data alert the dermatologist to adjust the treatment whenever necessary (e.g., dose, switch treatment, combination with other treatment); moreover, this tailored treatment is expected to be better tolerated and adhered to by the patient.

In the end, after completion of treatment, HRQoL scores of a patient can be compared with scores before treatment. An improvement in HRQoL, which is a main treatment goal for many patients, can be monitored, and may indicate treatment effectiveness.

**Improvement of treatment outcome**

Although the aforementioned functions suggest that application of HRQoL primarily has a positive effect on the process of health care, a positive effect on the outcomes of dermatologic treatment itself is expected as well. Empowerment of the patient, patient-centered health care, an optimal choice for treatment, monitoring treatment over time, and the explicit attention to HRQoL and/or the patient’s point of view is likely to have a positive impact on the patient’s HRQoL, treatment satisfaction, and disease severity. As evidence suggests that clinical and psychological outcomes, such as adherence to treatment advice, are optimized when patients’ emotional concerns are addressed, it is critical to recognize and manage the psychological needs of patients.

Because of lack of evidence in dermatology concerning the aforementioned functions, a randomized controlled trial (Dutch Trial Register, NTR1364) was started to assess the efficacy of HRQoL assessment and HRQoL communication in dermatologic practice. The study is ongoing and we expect to publish the results in 2012.
HRQoL assessment is particularly relevant for patients with chronic skin diseases that exert a large, negative impact on HRQoL. Psoriasis and eczema have been found to induce substantial decreases in patients’ HRQoL. These skin diseases also have high incidence rates, a high degree of chronicity, and may require long-term treatment; however, many more skin diseases affect HRQoL adversely, including acne, alopecia areata, hand/foot eczema, hidradenitis suppurativa, lichen planus, lichen sclerosus, pruritus/prurigo, seborrhoeic eczema, ulcers, urticaria, and vitiligo.

In addition to a specific diagnosis, the degree of disease severity, social visibility of the condition, age, personal circumstances, and the presence or absence of social support may influence patients’ HRQoL. So, a patient with severe psoriasis may experience a relatively good HRQoL, whereas another patient with only a mild degree of eczema may experience a relatively poor HRQoL. Assessments are thus relevant whenever a negative impact on HRQoL is suspected and whenever treatment does not meet the patient’s expectations.

The treatment setting itself may also play a role in selecting patients for HRQoL assessment. The inclusion of patients may be influenced by local policy, local conditions, presence or absence of facilities, and availability of staff. For instance, some dermatologists prefer to integrate HRQoL assessment in inpatient care or in a day care center rather than in outpatient settings. This preference may arise from the availability of sufficient room, accommodation, and staff; longer duration of treatment; and/or feasibility of counseling. Others prefer integration in specific outpatient consultation hours, for instance a biologic therapy consultation hour in a psoriasis treatment center.

Although HRQoL assessment can be applicable to all aforementioned patients and settings, we do not recommend assessments in all attending patients. In patients with a skin disease that hardly affects their HRQoL, such as in most patients with actinic keratoses, naevi, warts, and onychomycosis, or in skin diseases where a single consultation or short-term treatment is sufficient, it does not appear to be of relevance. Last, HRQoL assessment should not induce aversion or resistance, for instance in patients who consider questions on psychosocial functioning as unnecessary, intrusive, or inappropriate.

HRQoL questionnaires

There are simple ways to ask patients about their HRQoL, for instance by asking “How does your skin disease affect your daily life?” In fact, many dermatologists do ask patients how they are doing, and many patients do inform their dermatologists spontaneously about the impact of their skin disease on aspects of HRQoL, for instance on their mood, work, or family life. To collect data in a more objective and systematic way, however, reliable and validated HRQoL questionnaires may be required.

HRQoL questionnaires consist of a number of items or questions, most often to be answered by ticking off a multiple-choice answer. Multiple-choice responses may refer to intensity (e.g., from “mild” to “severe”) or frequency (e.g., from “never” to “all the time”) or may invite an opinion
with respect to given statements (e.g., from “strong disagreement” to “strong agreement”). Because HRQoL is a multidimensional construct (e.g., consisting of a physical, psychological, and social functioning domain), responses may result in domain scores, as well as an overall score. Currently, many questionnaires are available. In general, these can be distinguished into generic and specific HRQoL questionnaires. Generic questionnaires can be used for the measurement of HRQoL in all kinds of diseases and in the general population, whereas specific questionnaires are designed for the measurement of HRQoL in a specific disease, subgroup of disease, group of diseases, or patient population. Within dermatology, we distinguish dermatology-specific questionnaires designed for all kinds of skin diseases, and disease-specific questionnaires designed for a specific skin disease, for instance eczema or rosacea. The selection of an HRQoL questionnaire will depend on many factors, such as the functions it has to fulfill in clinical practice, the specific populations of patients, local policy and local conditions, and the psychometric characteristics of a specific questionnaire.

One could start using a simple, practical question to screen HRQoL, for instance a “questionnaire” consisting of only one question with multiple-choice responses: “To what extent does your skin disease affect your quality of life?” A more comprehensive questionnaire is the Dermatology Life Quality Index (DLQI), originally developed for routine dermatologic practice. The DLQI consists of only 10 questions and mainly focuses on limitations, for instance limitations in daily and social activities.

De Korte and colleagues and Both and colleagues systematically reviewed the quality of generic and dermatology-specific HRQoL questionnaires that are used in dermatology. For research, they recommended the use of a generic questionnaire in combination with a dermatology-specific questionnaire. A dermatology-specific questionnaire was explicitly recommended, as it encompasses all relevant dermatologic aspects and domains that a generic questionnaire may not include. For dermatology, the dermatology-specific questionnaire Skindex-29 was recommended.

Based on these reviews, we have chosen the Skindex-29 as the questionnaire of first choice for dermatologic practice in the Netherlands. Therefore, in this article we illustrate application of HRQoL assessment with the Skindex-29; however, there could be many reasons for making a different choice in different situations.

The Skindex-29 is a multidimensional questionnaire, assessing HRQoL during the past week, and consisting of 29 items that form 3 domains: symptoms, emotions, and functioning. Box 1 provides an overview of all Skindex-29 items, categorized per domain. Items are answered on a 5-point scale: Never = 0, Rarely = 25, Sometimes = 50, Often = 75, and All the Time = 100. The overall and domain scores are expressed on a 100-point scale, where higher scores indicate lower levels of quality of life. One item (item 18) about possible side effects of medication and/or treatment has been added to the questionnaire, but is not included in one of the domains, nor in the calculation of the overall score and domain scores. Research on the psychometric characteristics of the Skindex-29 indicated its reliability and validity. The Skindex-29 is currently available and psychometrically tested in many languages, including English, Dutch, French, German, Italian, and Spanish.
Box 1. An overview of Skindex-29 items categorized per domain.

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>Emotions</th>
<th>Functioning</th>
<th>Side effects</th>
<th>Electronic HRQoL assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My skin hurts</td>
<td>3. I worry that my skin condition may be serious</td>
<td>2. My skin condition affects how well I sleep</td>
<td>18. I worry about side effects from skin medications/treatments</td>
<td>Assessment of HRQoL with a paper questionnaire has the advantage of simplicity. Nevertheless, it has several disadvantages. Apart from all the paper work, and the integration of data into the</td>
</tr>
<tr>
<td>7. My skin condition burns or strings</td>
<td>6. My skin condition makes me feel depressed</td>
<td>4. My skin condition makes it hard to work or do hobbies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. Water bothers my skin condition (bathing, washing hands)</td>
<td>12. I am ashamed of my skin condition</td>
<td>8. I tend to stay at home because of my skin condition</td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. My skin is irritated</td>
<td>13. I worry that my skin condition may get worse</td>
<td>11. My skin condition affects how close I can be with those I love</td>
<td></td>
<td></td>
</tr>
<tr>
<td>24. My skin is sensitive</td>
<td>15. I am angry about my skin condition</td>
<td>14. I tend to do things by myself because of my skin condition</td>
<td></td>
<td></td>
</tr>
<tr>
<td>27. My skin condition bleeds</td>
<td>21. I am embarrassed by my skin condition</td>
<td>17. My skin condition makes showing affection difficult</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>23. I am frustrated by my skin condition</td>
<td>20. My skin condition affects my interactions with others</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>26. I am humiliated by my skin condition</td>
<td>22. My skin condition is a problem for the people I love</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>28. I am annoyed by my skin condition</td>
<td>25. My skin condition affects my desire to be with people</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>30. My skin condition makes me tired</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Electronic HRQoL assessment

Assessment of HRQoL with a paper questionnaire has the advantage of simplicity. Nevertheless, it has several disadvantages. Apart from all the paper work, and the integration of data into the
medical record, it also implies the calculation of domain and overall scores by hand. Previous research showed that pen-and-paper HRQoL questionnaires that have to be scored by hand take too much time and are costly in the long-term. Electronic assessment, on the other hand, may lower the resource burden and thereby encourage a more widespread use in clinical practice.

To facilitate the application of HRQoL assessment in dermatologic clinical practice in the Netherlands, an electronic version of the Skindex-29 was developed. This enables patients to complete the questionnaire on a computer by touching the answers of choice on the screen. To our knowledge, this is the only dermatology-specific HRQoL questionnaire that is currently available as an electronic application. Completion of the electronic Skindex-29 takes no longer than five minutes and, immediately after answering all questions, all data are available: an overview of questions and answers arranged per domain, and an overview of scores visualized in a bar chart. Both can be printed, and answers that are bothersome, that is, marked with “often” or “all the time,” are displayed in bold on the screen as well as in the printout.

International research indicates that electronic HRQoL assessment is increasingly applied within other specialties (e.g., oncology and hepatology) and has many advantages for clinical practice. Of course, a main advantage of this electronic version, compared with the paper version, is that answers and scores are immediately available and, thereby, facilitate “real-time” discussion with the patient, directly after the assessment (Figure 1). For this discussion, answers are displayed on screen, but it is preferable that both the dermatologist and the patient have a printed overview of the results as well. Answers in bold can serve as guidance during the patient’s consultation with the dermatologist, and the patient may take home the print-out, enabling him or her to discuss the results with significant others. The dermatologist may easily include the printed overview of HRQoL results in the patient medical record or may link the results to an electronic patient record.

Another advantage of the electronic version, compared with the paper version, is that patient’s answers and scores are saved in a Skindex file and are automatically transferred to an MS Excel file. Saved scores can be used to analyze data on a group level and to follow the course of HRQoL of an individual patient over time: repeated assessments are graphically

Figure 1. Discussion of domain scores with the patient, directly after the self-assessment on a computer.
presented in a single bar chart (Figure 2). In this way, the treatment process of a specific patient can be monitored and the effect of a treatment can be determined. Anonymous scores on a group level can be used for scientific research as well.

**Interpretation of scores**

To use HRQoL data in clinical practice, scores should be interpreted promptly and accurately; however, the interpretation of scores of any HRQoL questionnaire is not straightforward and has little of no direct meaning. A score of 18 or 63 on a scale running from 0 to 100 cannot be interpreted without additional resources. Two types of methods to establish a clinically meaningful interpretation of HRQoL scores exist: distribution-based and anchor-based methods. For interpretation of scores on the aforementioned DLQI we refer to Hongbo and colleagues. In the case of the Skindex-29, a first psychometric study on the distribution of Skindex-29 scores among 454 Italian patients with various skin diseases resulted in a categorization of levels of severity, namely “very little,” “mild,” “moderate,” “severe,” and “extremely severe.” This study, using a distribution-based method, was a first attempt to interpret Skindex-29 scores. In a study performed in the Netherlands among 339 patients at 9 general dermatologic outpatient clinics, Prinsen and colleagues used an anchor-based method to identify patients with mild, moderate, and severe impairment of HRQoL. The resulting cutoff scores for the Skindex-29 are presented in Table 1. To illustrate this: a patient with a score of 39 or higher on the emotions domain is likely to have a severe impairment, and a patient with a score of 32 or higher on the functioning domain is likely to have moderate impairment of HRQoL. At first glance, these cutoff scores are not easy to apply in clinical practice; however, by using different colors in the bar chart (green for mild, yellow for moderate, and red for severe impairment), one is able to make prompt interpretations at a glance. To facilitate the application of the cutoff scores, one may also, as a rule of thumb or memory aid, round off the cutoff scores for mild, moderate, and severe impairment of HRQoL to 20 or higher, 30 or higher, and 40 or higher, respectively, with the exception of the symptoms domain. Patients with scores equal to or above the presented cutoff scores for “severe” (see Table 1) in at least 1 of the 3 domains are significantly affected by their skin disease. Prinsen

![Figure 2. Repeated assessments of Skindex-29 over time: an overview of domain scores.](image)
and colleagues’ indicated that these scores may signal a need for (adjustment of current) treatment or for additional care or support, but that scores do not automatically indicate what kind of treatment, care, or support is appropriate, and therefore the specific needs of an individual patient should be explored in direct contact with the patient. Although the preceding paragraphs provide some guidance in the interpretation of scores and answers, it may be clear that discussion with the patient may yield important additional information and promote a patient-specific interpretation.

Discussion of HRQoL data

Once a patient has completed the questionnaire, the summation of the domain scores provides a specific profile of a patient’s HRQoL. This profile may indicate which domain of HRQoL was influenced most during the preceding week. Because large differences may exist among the 3 domain scores of a patient, it is important not to discuss the overall score solely, but to focus on the domain scores separately. In fact, 2 patients may have about the same overall score, but when taking the domain scores into account, it might appear that the impact of the skin disease focuses on different domains of HRQoL. This is illustrated in Figure 3.

To focus on HRQoL in greater detail, answers to single questions might also be of relevance. In fact, we recommended this, as single questions often provide relevant, additional information that can be used in clinical practice. For instance, a patient may have a low symptoms score but could have indicated “often” or “all the time” to the question about itch, or a low functioning score but with answers “often” or “all the time” to questions about tiredness or sleep. This may signal patients’ specific needs. In Box 2, a case is described to illustrate the relevance of HRQoL assessment in dermatologic practice, using the Skindex-29 as an example.

SUMMARY

The aim of this article was to contribute to the discussion on and the implementation of HRQoL assessment in routine dermatologic practice. With respect to the relevance of HRQoL assessment, we focused on self-awareness and empowerment, patient-centered health care, and optimal dermatologic treatment. With respect to patients, we focused on patients with a chronic skin disease in which substantial and enduring adverse effects on

---

Table 1. Identification of patients with mild, moderate, and severe impairment of HRQoL according to Prinsen and colleagues.

<table>
<thead>
<tr>
<th>Level of Severity</th>
<th>Symptoms</th>
<th>Emotions</th>
<th>Functioning</th>
<th>Overall</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>≥39</td>
<td>≥24</td>
<td>≥21</td>
<td>≥25</td>
</tr>
<tr>
<td>Moderate</td>
<td>≥42</td>
<td>≥35</td>
<td>≥32</td>
<td>≥32</td>
</tr>
<tr>
<td>Severe</td>
<td>≥52</td>
<td>≥39</td>
<td>≥37</td>
<td>≥44</td>
</tr>
</tbody>
</table>

HRQoL are suspected. With respect to implementation in routine practice, we described the application of the electronic version of the Skindex-29 in the Netherlands. We realize we have presented an optimistic view on HRQoL assessment in clinical practice. We would like to stress that a clinically meaningful interpretation of scores and the implications for dermatologic treatment and care are not self-evident. We already referred to a systematic review in which no unambiguous conclusion could be drawn with regard to the effect of PRO assessment in clinical practice; and even in our local, Dutch situation, there are some drawbacks to report. For instance, installation of the Skindex-29 software was sometimes complicated by technical limitations, such as information technology system requirements or safety boundaries that differ from organization to organization. Another problem in some of the clinics was lack of accommodation and staff, and budget problems with respect to computers, laptops, or pocket computers for the patients. Meanwhile, to overcome some of the technical limitations, a Web-based version of the Dutch Skindex-29 has been developed. This Web-based version enables patients to gain access to the Skindex-29 from any computer with an Internet connection. In the Netherlands, a considerable percentage of the citizens have a personal computer with an Internet connection at home. As Skindex data are saved on an external, protected server, potential technical problems during installation of software or constraints owing to safety requirements in a clinic are avoided. In the future, other HRQoL and PRO questionnaires can be added, thus resulting in a “Web portal” for PROs.

Figure 3. Skindex profiles: examples of random patients with eczema (a) and vitiligo (b).
Health-related quality of life assessment in dermatologic practice

**Box 2.** A case to illustrate the relevance of HRQoL assessment in dermatologic practice as measured with the Skindex-29.

Female, 26 years, psoriasis since the age of 7. Until the age of 20, psoriasis was under control with topical agents and phototherapy. Since then, the patient had extensive psoriasis, active without treatment. Only during pregnancies did the patient have a relatively stable disease. The patient had been on sickness leave regularly.

During the past 6 years, the patient used several systemic agents and underwent several intensive outpatient treatments, resulting in a temporary effect. After the last systemic treatment, her psoriasis aggravated. At that moment, her Psoriasis Area and Severity Index (PASI) was 25.

The patient acted relatively introverted, gave the impression of being very tired, and provided a more favorable picture of herself and her burden of disease than warranted. Skindex-29 assessment resulted in the following domain scores: Symptoms 96, Emotions 78, and Functioning 75.

During the consultation, Skindex-29 scores were discussed with the patient. The patient indicated that she had avoided social contacts and public places on several occasions because of her skin condition, and that there were some problems in handling psychic stress. The possibility of referral to a primary care psychologist for additional treatment with cognitive behavioral therapy was discussed. Also, support from a psoriasis patients’ organization was mentioned.

By discussing HRQoL data, the patient became more aware of the consequences of her skin condition and the need to address her problems. At that moment, the patient preferred to wait with additional treatment by a psychologist, but did decide to join the psoriasis patients’ organization. During a shared decision-making process concerning the patient’s treatment, it was decided to start treatment with a biologic.

Treatment with the biologic agent exerted a rapid improvement. After 4 weeks, Skindex-29 assessment was repeated, showing reduced domain scores: Symptoms 57, Emotions 60, and Functioning 46.

It became evident that the patient did understand the cause of her fatigue more clearly and, thereby, was able to change her coping behavior. Because of contacts with the psoriasis patients’ organization, the patient became more outgoing, showed a more open attitude, and talked about her problems more easily with others. Additional therapy was waived.

in dermatology. For instance, questionnaires measuring disease severity from a patient’s perspective, adherence, or treatment satisfaction.

Although the available evidence on the added value of HRQoL assessment for clinical practice, especially the application of PRO assessment in general, is ambiguous, we believe that initiatives to integrate HRQoL data into the management of patients are most welcome, and will help create a more solid body of evidence. If HRQoL is considered to be an important outcome of routine dermatologic treatment, would it not be a bit “careless” not to measure this patient-reported outcome?

**ACKNOWLEDGEMENTS**

The authors thank the members of the Dutch Working Group “Quality of Life Assessment in Dermatologic Practice” (in alphabetical order): MTW Gaastra, MD; DB de Geer, MD; AY Goedkoop, MD, PhD; CLM van Hees, MD; WJA de Kort, MD; CM Legierse, MD; TEC Nijsten, MD, PhD; MCG van Praag, MD, PhD; MLA Schuttelaar, MD; AME Visser–van Andel, MD.
REFERENCES


23. Finlay AY, Khan GK. Dermatology Life Quality Index (DLQI) – a simple practical measure for...


