The Evolution of Quality of Life Assessment and Use in Dermatology

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Keywords

Quality of life · Dermatology · Guidelines · Core outcome sets · Quimp

Abstract

The creation of the Dermatology Life Quality Index (DLQI) questionnaire facilitated many studies on the impact of skin diseases on patients' quality of life (QoL). Many national and international guidelines recommend QoL assessment in dermatology, and some of them contain detailed recommendations on treatment goals and changes of treatment approaches based on DLQI score banding and minimal clinically important difference. The methodology of QoL instrument development and validation is constantly becoming more rigorous. Initiatives on selection of core outcome sets for skin diseases are focused on clinical trials but may also be beneficial for clinicians. There are various benefits of using QoL information in clinical practice, but experience of this is very limited at the moment. QoL assessment in dermatology is a rapidly developing field with a gradual shift from theory to practice.

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For many years practitioners and researchers have been aware of how skin diseases affect different aspects of patients' lives and how successful treatment may improve patients' quality of life (QoL). In 1972, Dahl and Comaish [1] considered that psoriasis treatment was "good" if there was lessening of the extent of lesions or scaling, that led to a clear improvement in the patient's social or working life. The creation of the Dermatology Life Quality Index (DLQI) questionnaire by Finlay and Khan [2] in 1994 facilitated many studies on the impact of skin diseases on patients' QoL [3]. That measure was rapidly used in clinical trials for the assessment of treatment efficacy in parallel with measures of clinical severity [4]. The DLQI was translated into different languages, and many other dermatology-specific and disease-specific QoL instruments were developed. In the age of "precision medicine," the consideration of QoL allows a specific focus on a new dimension, the very personal problems and needs of a patient. There has been major progress in the field of QoL studies, highlighted by the introduction of a multitude of validated instruments for measuring what previously has only been felt [5]. Novel and growing areas of science usually generate creative conditions for the formation of new terminology. In 2017, Finlay proposed the new word

“quimp” to encapsulate the concept of “QoL impairment” [6]. The main purpose was to facilitate the integration of thinking about QoL into routine clinical practice. Having a single word might also accord the subject more importance. The EADV Task Force on QoL and Patient-Oriented Outcomes recommends the word “quimp” for routine clinical and research use [7].

Instruments for Health-Related QoL Assessment in Dermatology

Despite there being many different QoL instruments, ranging from a single question “Do you think the treatment has improved your QoL?” to complicated instruments with multiple items and domains and using different scoring systems, none of them is ideal. While some measures have been developed using rigorous methodology, other instruments have been created and used in a single study without appropriate validation. QoL in dermatology has most commonly been assessed by means of generic instruments and/or dermatology-specific and disease-specific instruments [8]. Researchers and clinicians therefore have a wide choice of instruments. Several parameters may influence which are used. Both patients and dermatologists prefer brief instruments, and a short time needed for completion is crucial. Validation characteristics of the QoL instruments is another important parameter. Both “basic” and “advanced” validation methods are in use at the moment [8]. Well-validated instruments have a better chance of being widely used. Some measures have been based on a mixture of clinician opinion, literature review and patient input. However, for the most popular instruments used in dermatology the question content has always been based solely on the actual experiences of patients [9].

The DLQI is the most widely used QoL instrument in dermatology both for general use and in the majority of the separate skin diseases [3, 10, 11]. There are many disease-specific QoL instruments for patients with psoriasis, atopic dermatitis and acne. The differing scoring systems used for QoL instruments make it difficult to compare and interpret the results of clinical trials [12]. The existence of so many competitive instruments not only makes the choice difficult, but also decreases the interpretability and utility of the data obtained. Rzany [13] has recently suggested that the number of QoL questionnaires in use should be reduced to 5 or 6 and that the need for the development of further QoL instruments in dermatology should be clearly defined before any new questionnaire is

Table 1. HRQoL instruments

<p><i>Most widely used generic HRQoL instruments for adults</i></p> <p>Short-Form 36-Item Health Survey (SF-36)</p> <p>EuroQoL 5-Dimension (EQ-5D)</p>
<p><i>Most widely used dermatology-specific HRQoL instruments for adults</i></p> <p>Dermatology Life Quality Index (DLQI)</p> <p>Skindex-29</p>
<p><i>Dermatology-specific HRQoL instruments for children</i></p> <p>Children’s Dermatology Life Quality Index (CDLQI) (from 5 to 16 years)</p> <p>Infants’ and Toddlers’ Dermatology Quality of Life (InToDermQoL) (from birth to 4 years)</p>
<p><i>Some popular disease-specific HRQoL instruments</i></p> <p>Infants’ Dermatitis Quality of Life Index (IDQoL)</p> <p>Quality of Life Index for Atopic Dermatitis (QoLIAD)</p> <p>Childhood Atopic Dermatitis Impact Scale (CADIS)</p> <p>Cardiff Acne Disability Index (CADI)</p> <p>Acne-Specific Quality of Life Questionnaire (Acne-QoL)</p> <p>Skin Cancer Index (SCI)</p> <p>The Functional Assessment of Cancer Therapy – Melanoma (FACT-M)</p> <p>Psoriasis Disability Index (PDI)</p> <p>Scalpdex</p> <p>Chronic Urticaria Quality of Life Questionnaire (CU-Q2oL)</p>

created. However, there is still a lack of disease-specific QoL instruments for many rare skin diseases. Although in theory disease-specific instruments could be created for every skin disease, this would result in a confusing array of measures, impractical for clinicians to use routinely. The basic aspects of people’s lives affected by skin disease are largely the same, although with different emphases. This raised the prospect of developing a single questionnaire that could be used on patients with any skin disease, a crucial aspect of making QoL measurement practical in the clinic [9]. The most popular generic, dermatology-specific and disease-specific instruments are presented in Table 1.

HRQoL Assessment in Children with Skin Diseases

Dermatology-specific QoL instruments are usually validated within specific age limits. Even the Family Dermatology Life Quality Index [14], which can be completed by the family members of adults and children with skin disease of any age, is restricted to completion by adults [15]. QoL measures have age limits because the lives of

infants, children, teenagers and adults are so different. The Children's Dermatology Life Quality Index (CDLQI) was created in 1995 for the assessment of QoL in children aged 4 years and above with skin disease [16]. In order to allow interpretation of the CDLQI scores a banding system was validated [17]. The CDLQI has been translated into different languages and used in many studies [18]. It remains the only dermatology-specific QoL instrument for this age group. Two dermatology-specific instruments for adolescents with skin diseases were developed [19, 20] but have not yet been used in other published studies. Several disease-specific instruments (predominantly atopic dermatitis-specific) for children and their parents were developed. Numerous national guidelines for children with different skin conditions recommend health-related QoL (HRQoL) measurement as part of the assessment process, and HRQoL also plays an important role in educational programs for children with chronic skin conditions and their parents [21].

The absence of a proxy dermatology-specific HRQoL questionnaire for use in children under 5 years with skin conditions was a major drawback. This resulted in skipping of the assessment of HRQoL in this age group or attempts to use a disease-specific proxy questionnaire inappropriately as a dermatology-specific measure, and to use a dermatology-specific proxy tool for children under the minimal age limit validated for that questionnaire [21, 22]. The Infants' and Toddlers' Dermatology Quality of Life (InToDermQoL) dermatology-specific proxy instrument for the youngest patients (0–4 years) with skin diseases has recently been developed and initially validated [23]. The epidermolysis bullosa-specific module of the InToDermQoL questionnaire was also developed [24]. Thus, there are dermatology-specific QoL instruments for all age groups of patients with skin diseases and their family members.

The Problem of Cross-Cultural Inequivalence of HRQoL Instruments

Corless et al. [25] identified several problems related to cross-cultural equivalence of QoL measures: cross-cultural versus cross-national conceptual equivalence, cultural hegemony versus cultural validity, cultural equivalence versus verbal equivalence, fidelity versus appropriateness, privacy versus disclosure, appropriateness of format and resource utilization for translation. Nijsten et al. [26] discussed the problem of cross-cultural inequivalence of dermatology-specific QoL instruments. Even in

the case of equal total QoL scores in patients from different countries, the difference between separate QoL item scores may be significant [27]. The highest and the lowest scored items were similar but not identical across countries in comparative studies on QoL impairment in children with atopic dermatitis [28]. Dissimilarities in QoL assessment data between adult inpatients from different countries may be explained not only by cross-cultural inequivalence, but also by differences in patients' clinical characteristics [29, 30]. A promising and innovative approach is to create new QoL instruments by international groups of specialists, rather than within individual countries, as in the case of the European KIDSCREEN/DISAB-KIDS project [31]. The InToDermQoL [23] has had simultaneous creation and validation of items in all participating international centers, helping to avoid the problem of cross-cultural inequivalence.

HRQoL Assessment in Dermatological Guidelines

Many national and international guidelines recommend QoL assessment in dermatology. The National Institute for Health and Clinical Excellence (NICE) guideline on the management of atopic eczema in children [32] proposed the adoption of a holistic approach to the assessment of a child's atopic eczema, taking account of the physical severity of the eczema and its impact on QoL. This assessment should guide treatment decisions, and it was noted that no direct relation necessarily exists between physical severity of atopic eczema and impact on QoL. A guideline for the diagnosis and management of vitiligo [33] recommended clinicians to make an assessment of the psychological and QoL effects of vitiligo on patients and make the patient's improvement in QoL the most important outcome measure in therapeutic trials.

Most of the detailed recommendations on the interpretation and use of QoL scores in dermatology are focused on psoriasis. In 2005, Finlay [34] proposed a concept of psoriasis severity that included QoL measurement scores: "The Rule of Tens for current severe psoriasis from the clinician's viewpoint is: Current Severe Psoriasis = Body Surface Area involved >10% or Psoriasis Area and Severity Index (PASI) score >10 or DLQI score >10." The British Association of Dermatologists guidelines for biological therapy for psoriasis 2017 contain the following criteria for biological therapy: "Offer biologic therapy to people with psoriasis requiring systemic therapy if methotrexate and ciclosporin have failed, are not tolerated or are contraindicated and the psoriasis has a large

impact on physical, psychological or social functioning (e.g. DLQI or Children's DLQI >10 or clinically relevant depressive or anxiety symptoms)" [35]. Augustin et al. [36], however, showed that the proportion of patients meeting the European consensus criteria for moderate-to-severe psoriasis (PASI and DLQI >10) was 14.0%, although 45.3% attained at least PASI or DLQI >10. Thus, it is a matter of discussion whether it is reasonable to provide systemic treatment for psoriatic patients who have severe impact on their HRQoL but have less severe clinical signs. Most recently Finlay and Sampogna [37] underlined that it is not recommended to interpret the "Rule of Tens" in an absolute way and that the DLQI scores should be used to help the clinician take the most appropriate decision for individual patients, and not used to restrict clinical judgment.

The British Association of Dermatologists guidelines for biological therapy for psoriasis 2017, mentioned above, also contained criteria for reviewing biological therapy that are based on the DLQI's minimal clinically important difference: "Clinically relevant improvement in physical, psychological or social functioning (e.g. ≥ 4 -point improvement in DLQI)" [35]. Reich and Mrowietz [38] in their paper on treatment goals in psoriasis considered that if, after a defined period of time, at least 50% reduction of the baseline PASI and DLQI of not less than 5 is not reached, patients should be switched to another therapy, after a balanced discussion. A European consensus of 19 European experts on treatment goals for moderate to severe psoriasis stated that in a situation where the therapeutic response improved $\geq 50\%$ but $< 75\%$, as assessed by the PASI, therapy should be modified if the DLQI is > 5 but can be continued if the DLQI is ≤ 5 [39].

European S3 guidelines on the systemic treatment of psoriasis [40] stated that in daily practice it may be useful to define a second set of treatment goals that serve as "lowest hurdles" (i.e., a minimum of efficacy that should be achieved). If these goals are not met, a treatment should be regarded as inefficient and must consequently be stopped and replaced by another treatment option. A PASI 50 response and DLQI < 5 have been proposed as a potentially useful minimum efficacy goal. It was also stated that treatment goals should be monitored at appropriate intervals during long-term maintenance therapy (e.g., at 8-week intervals). The same European S3 guidelines, based on the DLQI banding [41], suggested the DLQI total score of 0 or 1 as a treatment goal. Such a score indicates that the HRQoL of the patient is no longer affected by psoriasis. It seems to be a correlation between an im-

provement in PASI and an improvement in the DLQI. The drugs that produce the highest PASI reduction by the end of induction therapy are also associated with the greatest reduction in DLQI. Although the complete clearance of skin lesions may be regarded as the ultimate treatment goal for psoriasis, a PASI 75 response has been proposed as a practical and realistic treatment goal [40]. Meanwhile, Torii et al. [42] in their study on infliximab considered that a PASI 90 response is necessary to achieve a treatment goal stated in the European S3 guidelines: a DLQI of 0 or 1 (no effect on patient's QoL). More recently Elewski et al. [43] in a study on secukinumab have shown that psoriatic patients with a PASI 90 response achieve greater health-related QoL improvements than those with a PASI 75–89 response and concluded that PASI 90–100 is a relevant therapeutic goal in moderate-to-severe psoriasis. Abrouk et al. [44] found a statistically significant difference in DLQI scores between the patients on adalimumab achieving PASI 75 and the patients achieving PASI 90 at week 24, but not at week 12, and did not find a statistically significant difference in DLQI between the patients on ustekinumab achieving PASI 75 and the patients achieving PASI 90 at week 24. The DLQI score descriptor banding system and/or minimal clinically important difference have also been used in clinical trials on skin diseases other than psoriasis: chronic spontaneous urticaria, rosacea and hidradenitis suppurativa [45–47].

HRQoL in Core Outcome Sets for Skin Diseases

The proposal to reduce the number of QoL questionnaires in use and standardize their implementation may unite practitioners, researchers, health care organizations and members of the pharmaceutical industry. The use of different outcome measures across clinical trials, especially in the investigation of similar interventions for similar patient groups, significantly limits the interpretation, comparability and clinical application of trial results. To overcome this limitation, core outcome sets are being developed – these are collections of agreed standardized outcomes that should be measured and reported in all clinical trials for a specific clinical condition. The Core Outcome Set Initiative within the Cochrane Skin Group (CSG-COUSIN) supports the development of core outcomes in dermatology [48]. Core outcome sets are consensus-derived minimum sets of outcomes to be assessed in a specific situation. Their use limits outcome-reporting bias, al-

lows comparisons across trials and strengthens clinical decision-making. The successful example of the use of core outcome sets in rheumatology indicates that core outcome sets have the potential to standardize and improve clinical trial methodology and thus improve the overall quality of the evidence base for health care decision-making [49].

Activities on the creation of core outcome sets for psoriasis, atopic dermatitis, vitiligo, acne and other skin diseases are ongoing [50–53]. Based on the Delphi method, panels of experts select domains to be included in core outcome sets, and the importance of the inclusion of QoL measures has been advocated by consensus in all these groups. For example, members of the Harmonize Core Outcome Measures for Atopic Eczema/Dermatitis Clinical Trials (HOME initiative) have agreed by consensus that the long-term control domain should include signs, symptoms, QoL and a patient global instrument [52]. The group on psoriasis selected 6 out of 20 initially proposed core domains: skin manifestations, psoriasis and psoriatic arthritis symptoms, QoL, investigator global assessment, patient global assessment, and treatment satisfaction [53]. However, despite the acceptance of the importance of QoL assessment, it has sometimes been problematic to select the best instrument. For example, participants of the HOME initiative meeting concluded that they had no recommendation of an instrument for the core outcome domain of QoL. Existing instruments were assessed for face validity and feasibility, and future work that will facilitate the recommendation of an instrument has been agreed upon [52]. The inclusion of specific QoL instruments in generally agreed core outcome sets would be a progressive and helpful step. However, as was stated above, none of existing QoL instruments is considered to be ideal: there is a risk that once core outcome sets have been accepted, “stakeholders” may not be interested in further development and improvement of QoL assessment techniques. This could result in a limitation of research activity in the field.

Results of HRQoL Studies in Skin Diseases

Not all research studies on QoL in dermatology have been related to clinical practice but nonetheless many have been of importance. Many skin diseases have a negative impact on patients’ lives and a large secondary impact on the patient’s family that is comparable with severe nondermatological conditions [54, 55]. Data on

the HRQoL impact of skin disease may serve as additional evidence of the importance of our specialty to health care authorities. This HRQoL impact is not identical across different skin diseases [56–58]. QoL assessment may be used in educational programs as well as a predictor of patients’ interest in such programs and a predictor of willingness to visit a dermatologist, likely compliance, adherence to treatment, clinical success and even survival [10, 11, 59–62]. Gender- and age-specific differences may also be found [63–67]. HRQoL data may contribute to the understanding of patients’ needs and to individualize consultations and the management of different groups of patients with skin diseases.

HRQoL Assessment in Routine Dermatology Practice

Although some clinicians use QoL instruments in their routine clinical work, there is very little published about such usage [68]. Van Cranenburgh et al. [69] discussed why QoL assessment is relevant for dermatological practice, which patients would benefit most from routine HRQoL assessment and how QoL assessment can be applied in clinical practice. In 2016 thirteen members of the EADV Task Force on Quality of Life independently listed the ways they thought that it may be advantageous to measure QoL in dermatological clinical practice. A total of 108 different ways of using QoL information in clinical practice were suggested. These were sorted into the following five categories: inform clinical decisions, clinician-patient communication, awareness of skin disease burden, informing the consultation and clinical service administration. The wide range of potential benefits identified may not only encourage clinicians to use these measures, but also highlights many areas requiring evidence to establish the true value of routine use of QoL measures [68].

Conclusion

The number of publications on QoL in dermatology has constantly grown each year over the last 20 years (<https://www.ncbi.nlm.nih.gov/pubmed/?term=quality+of+life%2C+dermatology>). Numerous dermatology-specific and disease-specific QoL instruments of different quality have been developed and used in research. Many national and international guidelines recommend QoL assessment in dermatology and some of them con-

tain detailed recommendations on treatment goals and changes of treatment approaches based on DLQI score banding and minimal clinically important difference. The methodology of QoL instrument development and validation is constantly becoming more rigorous. Initiatives on selection of core outcome sets for skin diseases are focused on clinical trials but may also be beneficial for clinicians. There are various benefits of using QoL information in clinical practice, but experience of this is very limited at the moment. QoL assessment in dermatology is a rapidly developing field with a gradual shift from theory to practice.

Key Message

A shift of quality of life assessment in dermatology from theory to practice is taking place.

Statement of Ethics

The author has no ethical conflicts to disclose.

Disclosure Statement

The author has no conflicts of interest to declare.

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