

Quality of Life Indices

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ABSTRACT

The measurement of the impact of skin diseases on patients' quality of life is important. This review explains the reasons for this, explains the main methods of measuring quality of life in dermatology and describes recent research in this area. Virtually all aspects of patients' lives can be affected by skin disease. It is important to be able to measure this effect for clinical, therapeutic and health service research, for political purposes and potentially to inform clinical decisions. Measurement techniques include general health, disease specific and dermatology specific questionnaires: experience with the Dermatology Life Quality Index (DLQI) is described. Utility measures can also be used to gain insight into the value that patients place on their disease. There are special issues relating to the assessment of quality of life in children: a cartoon version of a questionnaire has been developed to enhance patient friendliness. The lives of the families of patients with skin disease may be affected and this impact can also be measured. In the clinic, complex clinical decisions, for example relating to starting systemic therapy, may be aided by better knowledge of the impact of disease on individuals, but measures will only be helpful if clinicians can easily interpret scores: the concept of score banding to aid this is described.

KEY WORDS: Quality of Life, DLQI, PDI, Outcome measures

INTRODUCTION

Our patients' lives can be affected in many ways by their skin disease. This review describes the various ways in which skin disease is a burden to patients and explains why it is now essential for us to be able to measure this impact. The different techniques used for this measurement are explained and their recent use is reviewed. Current research is also summarized.

Virtually all aspects of our patients' lives can be affected. They may experience severe symptoms, especially itch, pain and discomfort, and can become profoundly

psychologically disturbed. Simple aspects of daily living such as shopping or looking after the home or garden may become difficult. The choice of clothes may be restricted and these may need to be washed or replaced more frequently. Social activities such as going out with friends or taking part in sports, swimming or other physical activities may become difficult, often because of a reluctance to allow others to see the diseased skin coupled with a fear of what others may think of the appearance. The itch, appearance, or for example the literal "handicap" of not being able to use the hands at a keyboard because of painful fissures, may interfere with work and the exhaustion of treatment and

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disturbed sleep may reduce concentration and make studying difficult. Personal relationships may be difficult to form or may be adversely affected. The sexual lives of patients may also be impacted by their skin disease. The treatment of skin disease may unfortunately have an initial effect of making quality of life (QoL) worse because of the difficulty of using topical creams and ointments.

The extreme effect that skin disease can have on our patients was tragically emphasized by a recent report of a teenager who committed suicide "because he was tormented by acne".¹ To a lesser but still deeply hurtful extent, many patients with psoriasis and other widespread skin diseases are barred from public swimming baths by ignorant or prejudiced attendants and patients are excluded from work with the public because employers are concerned about the possible reaction of their customers.

WHY WE NEED TO MEASURE QUALITY OF LIFE

There are several reasons why it may be helpful for dermatologists to be able to measure the effect that skin disease has on their patients' lives. Where dermatology services are under-resourced it is important that dermatologists can produce evidence that their patients may be profoundly affected by skin disease and that this effect is equivalent, or even greater than, the effect of some systemic diseases. This evidence may be helpful politically and has been used to strengthen political arguments relating to development of dermatology services.² In clinical research, the traditional outcome measures such as measuring area or scaliness of skin disease do not take into account the patient's view. Measurement of quality of life in addition to measuring signs gives an added perspective to the assessment of new therapies, and regulatory authorities are showing interest in such extra outcome measures. In research into the effectiveness of new methods of delivering health care, or in comparing existing alternative methods, the use of a patient-orientated outcome measure may be the most appropriate. Similarly where there is a requirement to audit clinical activity, quality of life measures may be effectively used.

At the moment very few clinicians formally assess the QoL of their patients. However most clinicians take into account their perception of the QoL of their patients when taking critical clinical decisions, for example starting isotretinoin in acne or methotrexate in psoriasis. Unfortunately clinicians are not as good at these estimations of QoL as they think they are.³ It may be that the use of information from a simple but formal validated QoL measure may assist the clinician in making more appropriate clinical decisions, and may have the added advantage of documenting clear justification for the use of drugs which are expensive or have associated risks.

Evidence of the growing awareness of the value of measuring QoL in India was seen at the IADVL Annual Conference in Mumbai in January 2004⁴ and in recent publications.⁵⁻⁷

METHODS OF QUALITY OF LIFE ASSESSMENT

There are several approaches to the design of questionnaires used for QoL measurement.⁸ In the design and creation of these questionnaires a series of validation steps need to be undertaken. These include the requirement that the information on which the questions are based comes from patient sources and that the questions are understandable by patients. The questionnaires need to be validated to check that they are answered consistently by patients and that the scores are sensitive to change if the clinical condition changes. There needs to be cross validity with other measures and the internal consistency of the questions needs to be established.

General measures

General measures, such as the SF-36 (Short Form-36), Euroqol-5 or Sickness Impact Profile, are designed to be used across all diseases. Information from their use is therefore very useful politically as they allow comparison of the effect of skin disease to the effect of non-skin disease. However they are usually not as sensitive to change as disease specific measures when used to measure change after an intervention. The SF-36 has been used to demonstrate that psoriasis causes as much disability as other major medical diseases, with

a reduction in physical and mental functioning similar to that seen in arthritis, hypertension and diabetes.⁹

Disease specific measures

Disease specific measures include the Psoriasis Disability Index (PDI), the Cardiff Acne Disability Index (CADI), the Acne-Specific Quality of Life Questionnaire (Acne-QoL), the Infant's Dermatitis Quality of Life index (IDQOL) and Psoriasis Quality of Life index (PSORIQoL), amongst others. There is now twenty years' experience of the PDI.¹⁰ The use of this 15 question measure has been described in at least 57 articles and published abstracts, and has been used in 20 countries in 13 languages. Examples of the way it has been used include a study of 6497 Nordic patients who were members of patient support groups. The data indicated that the Psoriasis Area and Severity Index (PASI) score was not a predictor of the QoL score, and that patient self-reported severity was the most significant predictor of QoL.¹¹ Although PASI may not be a predictor of QoL in individual patients, populations of patients treated with effective therapy will show an improvement both in PASI and PDI scores.¹²

Dermatology specific measures

After several disease specific measures had been described for use in dermatology, it became clear that different inflammatory skin diseases affect individuals in similar ways. It would be difficult and repetitive to create disease specific measures for every skin disease and there is a need for dermatology specific measures which could be used across all skin disease. Examples include the Dermatology Life Quality Index (DLQI),¹³ the Dermatology Quality of Life Scales (DQoLS),¹⁴ Skindex,¹⁵ the Dermatology-specific Quality of Life instrument,¹⁶ and a measure described in Germany, the DELH.¹⁷

The Dermatology Life Quality Index (DLQI)

The DLQI consists of 10 questions with simple tick-box answers scored from 0 to 3 (Figure 1).¹³ The mean answer time is two minutes.¹⁸ The DLQI has been described in at least 36 skin diseases in more than 130 articles and published abstracts, in 17 countries and 21 languages.¹⁹ Use of the DLQI has allowed new

Figure 1: The Dermatology Life Quality Index

The aim of this questionnaire is to measure how much your skin problem has affected your life OVER THE LAST WEEK. Please tick one box for each question.

1. Over the last week, how **itchy, sore, painful** or **stinging** has your skin been?
2. Over the last week, how **embarrassed** or **self conscious** have you been because of your skin?
3. Over the last week, how much has your skin interfered with you going **shopping** or looking after your **home** or **garden**?
4. Over the last week, how much has your skin influenced the **clothes** you wear?
5. Over the last week, how much has your skin affected any **social** or **leisure** activities?
6. Over the last week, how much has your skin made it difficult for you to do any **sport**?
7. Over the last week, has your skin prevented you from **working** or **studying**?
If "No", over the last week how much has your skin been a problem at **work** or **studying**?
8. Over the last week, how much has your skin created problems with your **partner** or any of your **close friends** or **relatives**?
9. Over the last week, how much has your skin caused any **sexual difficulties**?
10. Over the last week, how much of a problem has the **treatment** for your skin been, for example, by making your home messy, or by taking up time?

Please check you have answered every question. Thank you.

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Each question is answered either "Very much" (score 3), "A lot" (score 2), "A little" (score 1) or "Not at all" (score 0). Questions 3 – 10 also have the option "Not relevant" (score 0). The first part of question 7 has the choices "Yes" (score 3), "No", or "Not relevant". The second part of question 7 has the choices "A lot", "A little" or "Not at all". The maximum score (indicating highest possible impairment of quality of life) is 30 and the minimum 0. Further information: www.ukdermatology.co.uk.

insights into several aspects of clinical dermatology. We have shown, for example, that the greater the

disability of patients with psoriasis, the poorer their adherence (compliance) with topical therapy.²⁰ It seems likely that if QoL is severely impaired, patients become depressed or demotivated to treat themselves effectively, the psoriasis remains active or becomes worse, and so a vicious cycle is set up. An example of the use of the DLQI in India was the study by Parsad et al,⁷ examining the levels of QoL impairment of patients with vitiligo. Patients who had successful treatment had a lower impairment of their QoL than those patients in whom treatment failed.

The DLQI has been used to measure the effect of inpatient care on QoL, in a study which compared two university dermatology inpatient units in Miami, Florida, USA and Cardiff, Wales, UK.²¹ This study demonstrated that, despite the wide differences in patient mix and health care systems, the mean DLQI scores before and after admission were very similar, indicating parallel effectiveness and the clinical importance of this treatment strategy in both countries. Another use of this measure in health service research was to assess the effectiveness of outpatient consultation on QoL of patients. While patients were waiting for consultation, their DLQI changed only minimally, but in the ten weeks after consultation, there was a significant and greater improvement in the mean QoL scores.²²

After patients with contact dermatitis are patch tested their QoL scores improve,²³ and involvement of the trunk is associated with poor QoL. A recent review describes several QoL studies relating to contact dermatitis, patch testing and QoL.²⁴ The use of QoL measures in the developing world was recently illustrated by Etemisi,²⁵ who, using a Kiswahili translation of the DLQI, was able to describe the effects of different skin diseases on QoL in Tanzania.

Utility measures

The methods of measurement of QoL described above consist of specific questions about the actual experiences of patients. An alternative approach is to try to understand the “value” that patients place on their disease or on being healthy. This “utility” approach

can use hypothetical questions relating to time trade off or financial trade off. In one study using this approach, we asked patients, “If there was a simple permanent cure for your skin condition, how much would you be prepared to pay for the cure?” and gave a series of possible amounts.²⁶ Of patients with severe psoriasis, 71% stated that they would be prepared to pay £1,000 or more and 38% would have been prepared to pay £10,000 or more. More recently it has been shown that in psoriasis changes in QoL correlate between both willingness to pay and time trade off.²⁷

CHILDREN AND FAMILIES

The measurements described above all relate to adults, but all dermatologists realize that skin disease can also be very disruptive to the lives of children. There are even more problems in trying to measure QoL in children than in adults; however, a Children’s Dermatology Life Quality Index (CDLQI)²⁸ has been described and is widely used. There is high correlation in scores between the text alone and text with cartoon versions.²⁹ The cartoon version is generally preferred by patients compared to the text alone version. An example of the use of the CDLQI has been the measurement of the impact of vitiligo on children’s lives.³⁰

When an individual has skin disease there is often a secondary impact on the lives of the partner or family. A series of families of children with atopic dermatitis were interviewed in order to understand this impact and the information gained was used to create a Family Dermatitis Impact questionnaire.³¹ This can be used as a further outcome measure concerning intervention in atopic dermatitis.

WHAT DO QUALITY OF LIFE SCORES REALLY MEAN?

Although QoL measures have been used widely in research settings over the last decade, at present clinicians do not know how to interpret the scores for clinical use. In order for the scores to be clinically useful, it is necessary to know the minimal score change that is of importance to a patient and to have

some idea of the absolute meaning of scores from a patient's point of view.

In a pilot study it has been demonstrated that a score change of 5 or more in the DLQI does represent a change which is of importance to patients.³² In an attempt to understand the "absolute" meaningfulness of DLQI scores, nearly two thousand dermatology outpatients completed both the DLQI and a global question. This data was used to create descriptive bandings of DLQI scores.³³ Being able to better interpret the scores of QoL measures gives the potential of being able to more appropriately measure disease severity and hence define more appropriate protocols for the use of systemic and other therapies.

CONCLUSION AND FURTHER INFORMATION

This article has introduced some of the concepts concerning measurement of quality of life in dermatology. There is considerable potential for such measurement to be of value in informing clinical decisions, especially in an era of new potent therapies for widespread inflammatory disease.

Further information about QoL measures developed by the author and colleagues is found on www.ukdermatology.co.uk (click on Quality of Life). This site gives full texts and many translations of several questionnaires, gives instructions for their use and lists references describing their use.

DECLARATION OF INTEREST

Professor A Y Finlay is joint copyright owner of the PDI, DLQI, CDLQI, DFI, CADI and IDQoL. His department receives some funding from the use of these measures. Professor A Y Finlay has consultancy arrangements with various pharmaceutical companies, the products of some of these companies are referred to in the manuscript or reference given.

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