Skin Disease Disability: Measuring Its Magnitude

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Abstract. Skin diseases cause considerable discomfort, but usually do not affect patients' lifespan. However, the effects of skin disease on patients' lives can be profound, as all aspects of life can be interfered with. Methods to measure these effects on life quality are needed for clinical, research, audit and political reasons. General health questionnaires such as the Sickness Impact Profile or the Short Form 36 can be used to compare the impact of skin disease to the impact of diseases of other systems. Disease specific questionnaires such as the Psoriasis Disability Index, dermatology specific measures such as the Dermatology Life Quality Index (DLQI), and utility measures can all be used in dermatology and have their different specific indications. The use of the DLQI has quantified the major impact that inflammatory skin disease has on patients and has been used to demonstrate the improvement resulting from systemic therapy and from inpatient management. A version for use in children has also been described. The information gained from this work can be used to demonstrate the importance of adequately managing skin disease in the community and can help to guide resource allocation. (Keio J Med 47 (3): 131-134, September 1998)

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Introduction

Our patients with skin disease experience a wide range of effects of their disease on their lives, ranging from the trivial to major handicap. Discrimination is experienced, for example the young adult who is barred from using a swimming pool because of the ignorance and prejudice of the pool attendant. The aim of this article is to explain why skin disease handicap matters to all dermatologists, to explain what we know about it and why and how we can measure it. Our current work in this area is reviewed.

The World Health Organisation has various definitions of the terms used in this field. To take the dermatological example of a patient with severe hand dermatitis, the inability to properly move the hand because of pain and fissuring is the patient's "impairment". The consequence of this impairment is that your patient is unable to use her computer keyboard: this is the "disability". The disability results in the patient having to stop her employment as an administrator: this disadvantage in her fulfilling her normal role in society is the "handicap".

The Effects of Skin Disease on Patients

There are many descriptions both in the general and dermatological press about the effects of skin disease on patients. A recent newspaper in Wales carried an item describing how a businessman refused to be served by a waitress with acne, and Cunliffe has described how there is a much higher prevalence of unemployment among young adults with severe acne than in unaffected controls. Koo has also drawn attention to the considerable embarrassment and depression caused by acne.

Another example is that of patients with chronic and delayed pressure urticaria. Over half of a group of such patients reported time off work, and a third reported problems with sexual relationships because of this problem. In patients with the persisting problems of severe psoriasis, in the last month more than half had had problems with social activities, problems with clothes, and had had problems resulting from the treatment itself. That UK study echoed similar findings...
from a survey in the USA\textsuperscript{6} where over 70\% of patients with psoriasis had been inconvenienced by skin shedding over the previous month.

Atopic dermatitis poses severe burdens for affected adults, children and their carers. Information about 1944 children was given by their parents in a survey\textsuperscript{7} carried out by a UK patient self-help group, the National Eczema Society: in 60\% of children sleep had been disrupted. Psychological disturbance was much more common in children with severe atopic dermatitis than in a more mildly affected group.\textsuperscript{8} The family impact of atopic dermatitis was explored\textsuperscript{9} by in-depth interviews with families: this study revealed the resulting lifestyle restrictions and psychological pressures on other family members. These secondary effects can be alleviated quite rapidly by potent systemic therapy.\textsuperscript{10}

Chronic skin disease such as atopic dermatitis can have a major impact on the earning potential of sufferers: in a study of adults with severe persisting atopic dermatitis one third had lost significant income in the preceding year.\textsuperscript{11}

\textbf{Why Measurement of Handicap is Important}

It is important to be able to measure the impact of skin disease on quality of life for several reasons. First, in the clinic it might become helpful to have an objective measure of the handicap experienced by a patient, especially if new expensive or hazardous therapy is being contemplated. Second, for the purposes of clinical audit, it is useful to have a patient oriented tool to reflect the patient's view of the outcome of management. Third, in clinical research a measure of the impact of the disease provides information additional to the traditional objective records of skin changes. Finally in those health care systems where decisions concerning resource allocation are taken, dermatology often fares badly because of a lack of understanding of the major adverse effects of skin disease: information from the use of appropriate measures may help overcome this problem.

\textbf{How Quality of Life is Measured in Dermatology}

Several methods have been described to measure the impact of skin disease on patients' lives: these have recently been reviewed in detail.\textsuperscript{12} Techniques include general health questionnaires, disease specific questionnaires, speciality specific questionnaires and utility methods.

\textbf{General Health Measures}

The advantage of using a general health measure is that it is possible to compare the effects of skin disease on patients' lives to the effects of diseases of other systems. The UK Sickness Impact Profile for example had a mean score of 9.9 when completed by patients with severe psoriasis, compared to reported values of 7.0 in hypertension and 10.4 in cardiac failure.\textsuperscript{13} Similarly the general health measure, the Children's Life Quality Index, allows comparative data in children: mean scores of 3.8 have been reported in atopic eczema, 6.7 in asthma and 6.8 in children with diseases of the ear, nose or throat.\textsuperscript{14}

\textbf{Disease Specific Measures}

Several disease specific measures have been described\textsuperscript{12} including the Psoriasis Disability Index (PDI) and the Acne Disability Index (ADI). The PDI consists of 15 questions which originated from patients with psoriasis.\textsuperscript{15} Use of this measure has demonstrated that there is no simple relationship between the extent of the psoriasis and the resulting degree of handicap.\textsuperscript{15} Its use as an additional measure in clinical trials is able to demonstrate\textsuperscript{16,17} the relative benefit of therapy from the patient's point of view and its use has been validated in a large community study.\textsuperscript{18} In acne, a short five question version of the ADI, the Cardiff Acne Disability Index,\textsuperscript{19} can be easily used in a busy clinical setting, and has demonstrated rapid improvement in patients taking isotretinoin.\textsuperscript{20}

\textbf{Dermatology Specific Measures}

It is clear that what is required in dermatology is a simple, short, quickly self-administered questionnaire that has been validated and can be used across all skin diseases. Recently described measures include Skindex,\textsuperscript{21} Dermatology Life Quality Scales,\textsuperscript{22} and Dermatology-Specific Quality of Life.\textsuperscript{23} The measure with which there has been the most experience,\textsuperscript{24} since we described it in 1994,\textsuperscript{25} is the Dermatology Life Quality Index (DLQI) (Table 1). This consists of 10 questions with tick-box answers scored from 0 to 3, giving a maximum score of 30. The questions cover most of the ways in which skin disease can affect people, and the DLQI can be used to measure change in groups of patients or individuals, as well as comparing the effects of different skin diseases. It is possible, for example, to rank different skin diseases in order of their effects on patients: inflammatory diseases such as atopic dermatitis and psoriasis score more highly than moles or warts.\textsuperscript{25}

Instruments such as the DLQI can be used to gather information to demonstrate the value of some aspects of patient management. We used the DLQI in all patients admitted to the dermatology in-patient unit in Cardiff at the time of admission and four weeks after
discharge.\(^2^6\) This study showed a major improvement in DLQI scores in patients admitted with psoriasis or eczema. A similar study in Miami has confirmed the value of inpatient care in improving depression scores.\(^2^7\) Although disease specific measures exist for acne, the DLQI is also very sensitive to change in this condition.\(^2^8\) Not only is there a major improvement in DLQI scores at the end of isotretinoin therapy, but this benefit is maintained for at least a further eight months. In contrast, the DLQI can also be used to show how little patients’ lives can be disturbed by a potentially serious condition such as a basal cell carcinoma.\(^2^9\) The low scores seen in this condition underline how quality of life measures must never be used as the only criteria for judging the “importance” of a disease.

Skin disease can have a major impact on the lives of children, but questionnaires designed for adults are obviously not appropriate for use in this age group. The Children’s Dermatology Life Quality Index (CDLQI),\(^3^0\) based on information gained from children with skin disease, is an attempt to meet the need for a suitable measure. As with the DLQI, the highest scores are seen with widespread inflammatory disease such as atopic dermatitis and scabies. Inpatient treatment for childhood atopic dermatitis results in a dramatic improvement in scores.\(^3^1\) A new more attractive colour cartoon version of the CDLQI, using the same text, is currently being validated.\(^3^2\)

### Utility Measures

Utility measures are a way of assessing the “value” that a patient places on their disease. Methods used include time trade-off questions, disease comparison questions and hypothetical financial comparison questions. As an example, we asked patients with severe psoriasis how much time they would be prepared to spend on treating their skin each day, if there was a daily treatment which kept their skin completely normal for the rest of that day. 75% of patients said that they would be prepared to spend one hour or more, and 33% said they would be prepared to give up three hours daily for the sake of normal skin.\(^5\) In another study\(^1^1\) we asked patients with severe atopic dermatitis how much they would be prepared to pay for a cure, if there was a simple complete permanent cure for their skin condition. 71% said they would be prepared to spend £1,000 or more and 38% said they would spend £10,000. When their income was taken into account, patients with atopic dermatitis would be prepared on average to spend about three-quarters of one annual income for the sake of a cure. When asked a related question, 99% of patients with hair loss would prefer a cure rather than to be given £1,000 cash.\(^3^3\)

We wished to determine how patients with skin disease viewed their own problems, compared to those that they perceived patients with other diseases suffered. We asked patients whether it would be better, the same or worse, compared to their skin condition, to have diabetes.\(^5\) We also posed a similar question about a number of other comparitor diseases. Patients with severe psoriasis mostly felt that it would be worse to have the other diseases rather than have psoriasis. However, those patients who coincidentally also suffered from the comparitor disease overwhelmingly thought that it was worse to have psoriasis.

### Conclusion

The study of the effects of skin disease is still a relatively new area of interest. There is still much to be learnt and new methodologies are being described. One example, the Patient Generated Index, which asks patients to list the five most important ways that their lives are affected, has been used in atopic dermatitis.\(^3^4\) We are completing a multi-centre study using the DLQI in patients at the time of referral for specialist advice, at the time they are actually seen, and six weeks later. Preliminary analysis indicates that there is little overall change in scores whilst awaiting the appointment, but a significant improvement in the weeks after seeing the dermatologist.\(^3^5\) Information from this study can be used to formulate waiting list priority criteria and to identify which patients are most helped by consultation with a dermatologist.

Although it is not realistic or appropriate to expect quality of life measures to be used in a routine way in every consultation, there are good reasons to consider using them. Their use demonstrates your concern to your patient and can act as a focus to discussion. They may provide extra clinical information, aiding some clinical decision taking concerning management and their repeated use can demonstrate improvement or deterioration in a patient’s condition. This paper has
reviewed the other reasons why measurement of quality of life in dermatology may be of benefit and has given some guidance about the methods available.

References on the Internet

A complete list of publications from the author concerning quality of life in dermatology is available on: http://www.uwcm.ac.uk/uwcm/dm/stafinfo/qol.html

References