

# Community Dermatology

## Quality of life

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### Introduction

The prevalence of skin disease is very high worldwide, causing extensive damage to people's lives and productivity. But skin disease rarely kills and so is often ignored and dermatology services under resourced. A major challenge over the last 30 years has been to develop methods to measure the impact of skin disease on the individual and on society. With measurement methods now available it is possible to quantify the huge impact of skin disease and so provide powerful new arguments for an appropriate share of healthcare funding for services and research. It is possible to prove and compare the improvement from different management strategies and identify the most cost effective ways to intervene to improve quality of life of people with skin disease. This review describes the ways in which skin disease affects individuals and their families, outlines the methods to measure these impacts, and details how having these simple questionnaires can transform our understanding of clinical needs for the individual and planning for a community.

### Current impact on the individual

Skin disease can affect virtually every aspect of a person's life (1,2). Many people with skin disease were interviewed to find out the patients' perspective on how their lives were affected (3). The main areas were symptoms and feelings, daily activities, social activities, personal relationships and work or study. In addition the treatment for the skin disease itself often added an extra burden because of the time needed to apply ointments and because of resulting messiness and soiling of clothes, furniture and office equipment.

The symptoms experienced are itchiness (the major skin symptom), soreness, pain and stinging. These symptoms often lead to sleep disturbance and resulting tiredness. People frequently report

feeling embarrassed and self-conscious and these feelings contribute to changes in behaviour with family and friends.

Social and leisure activities are altered by skin disease, as well as the ability to look after the home or undertaking simple basic activities such as shopping. Sporting activities are often avoided, often because of a desire not to reveal abnormal skin to strangers, for example in changing rooms. Many people avoid going swimming.

## **Work**

People's ability to work can be severely impaired. If your hands are oozing and tender because of severe eczema it is not possible to use a keyboard. If you have visible psoriasis on the back of your hands you might have to stop working as a waiter serving food, because of the widespread lack of understanding about skin disease and associated prejudice and stigma. If you are a student, the constant itchiness and sleep loss may make it hard to concentrate on your studies and exam grades may suffer, with resulting impact of employment. The economic wellbeing of the patient depends on being able to work, but not working places a large burden also on society: others have to pay for the person's care and the person's lost productivity is a loss to the wider society.

Close relationships with friends and partner can be affected, unless there is great understanding and sympathy. Sexual difficulties can be caused as the skin is an essential organ in sexual communication and pleasure.

The ways that a person can be affected by skin disease, described above, are the bases of the questions in the Dermatology Life Quality Index (DLQI) (3), a simple validated questionnaire used to measure the impact. However these questions only address one aspect of the impact of skin disease, i.e. the current impact on quality of life. There are two other important dimensions, time (Major Life Changing Decisions) (4) and family (the Greater Patient) (5).

## **Impact on Major Life Changing Decisions**

During an individual's life, a series of Major Life Changing Decisions (4) are made, including for example, what work to do, whether or not to marry or to have children, whether to move to a different area or country, whether to divorce or whether to retire. If you have a skin disease at the time that a major decision is being taken, the influence of that decision is likely to reverberate years down that person's life. Even though the disease may later clear, the impact of the major decision is still active. Skin disease can frequently adversely influence these critical decisions.

## **Impact on the Greater Patient – the partner and family**

It is not only the patient's life that is affected by skin disease. If your partner has widespread psoriasis, there are many ways in which your life will be affected, from the obvious helping with treatment to the less obvious restrictions on your leisure and holiday plans, and the financial impact on your household. If your child has severe atopic dermatitis, you may have frequent disturbed nights and your relationship with your partner and other children may be strained. We have described the close circle of partner and family as the Greater Patient (5) to emphasise the importance of this affected circle of people. In some situations, the family member's life is more affected than the patient herself.

## **Quality of life and psychological disturbance**

Skin disease can have a profound psychological impact on a person, and the individual's personality will shape their response to having abnormal skin. There is therefore an interrelationship between the psychological makeup of a patient and the overall impact of the skin disease on the resulting impact of the disease on their life quality.

### **Measurement of quality of life**

Measurement of the impact of skin disease on health-related quality of life can be with validated standard questionnaires, or by using utility questions (such as time trade-off) (6). Questionnaires are designed to be used across all diseases, or across all diseases in a particular specialty (such as dermatology) or in one disease only.

General measures include the widely used Short-Form 36 (36 questions), the EuroQoL (5 questions) and the recently validated WHOQOL. They have all been used in dermatology and are able to compare the impact of skin diseases with the impact of non-skin disease, demonstrating that psoriasis causes as much disability as other major medical diseases (7). Because the questions are not specific to dermatology, they are not the first choice to assess change following intervention.

Questionnaires for use across all skin diseases include the DLQI (3, 8) and Skindex (9). These can be used to compare one skin disease to another, and also to assess and monitor change. A critical review of health-related quality of life instruments (10) recommended a combination of the SF-36 and Skindex-29 as the instruments of choice in dermatology. Presumably this was for the research setting as the use of these two measures would be impractical in a busy clinical setting.

There are also many disease specific questionnaires including for example the Psoriasis Disability Index, PSORIQoL or Cardiff Acne Disability Index. Such measures have questions specifically relevant to the disease and so are very sensitive to change.

Most published work on the impact of skin disease focuses on the problems of adults. However skin disease also affects the lives of infants, children and adolescents. There are specific questionnaires for these people, including the Infants' Dermatology Quality of Life questionnaire, the Children's Dermatology Life Quality Index (11) and the Skindex-Teen. The secondary impact on the lives of the patients' partners and other family members, the Greater Patient, can be measured using the Family Dermatology Life Quality Index (12).

The concept of utility measures explores a patient's attitudes to their condition and attempts to express the hypothetical value that the patient places on being disease free, using time or financial trade off questions. The Quality Adjusted Life Year (QALY) concept expresses how many years of life shortening would be equivalent to living entirely disease free: QALY calculations based on quality of life data are used by the UK National Institute for Clinical Excellence to inform decisions about new drug availability.

An attempt has been made to quantify the burden of skin diseases, estimating direct, indirect and placing a value on "intangible quality of life impact", based on calculated DLQI data, for the USA

population (13). The total estimated cost for 2004 came to US\$95,000 million, including a figure of \$56,000 for the quality of life impact.

## **Meaning of scores**

There is little point in measuring a disease impact if the score has no obvious meaning. The score descriptor bands for the DLQI (14) are simple to remember and so practical in a busy clinic. A score >10 means that the skin disease is having a very large effect on the patient's life, and so further active clinical intervention is indicated. There are also score bandings for the Skindex-29 (15).

## **Uses for measurement**

Apart from the wider ability to demonstrate the importance of skin disease in comparison to other disease, measurement of quality of life can be useful in clinical research, in epidemiology, to audit services and within the clinical consultation.

It is appropriate that new drugs, which may be very expensive, should be demonstrated to meaningfully improve life quality as well as improve the signs of skin disease. Clinical studies during the development of the biologics used in psoriasis have used QoL measures to amply demonstrate their effectiveness, providing comparative data (16). When other forms of intervention are introduced in a dermatology service, for example a General Practice based clinical service (17), the use of quality of life measures as a patient reported outcome measure provides relevant data.

In the clinic, quality of life data may, by informing clinicians, result in more appropriate decision taking, especially in the small but important proportion of patients whose lives are being very severely affected (18). The process of clinical decision taking is in reality very complicated and subject to many non-clinical influences as well as being partially science or evidence-based (19). Given the wide range of influences operating, it is very important that the information concerning quality of life impact is heard loud and clear above the noise of competing distractions.

If the quality of life of patients is monitored, as required for example by UK guidelines for use of biologics in psoriasis (20), the comparative data can be used to inform the clinician concerning dosage or when to change therapy. We have suggested that a simple formula involving quality of life data may be helpful in defining psoriasis severity. The Rule of Tens (21) states that if the Body Surface Area of involvement is >10% or the DLQI score is >10 or if the Psoriasis Area and Severity Index score is >10, then the patient has current severe psoriasis.

There is the potential to use quality of life data to assist decisions over resource allocation. For example, limited resources could be targeted at those conditions or patients in whom QoL impairment was high, if it is previously known that that condition is responsive to therapy. If the capacity for benefit is great, there is a strong argument for planning services to meet this need. For example venous leg ulcers cause great impairment of quality of life. Well-organised but relatively simple intervention may be very effective in healing such ulcers, with massive improvement in quality of life. It could be argued that such an ulcer service should be funded rather than a clinical service for another condition that resulted in little change in quality of life. There is now extensive information about the comparative levels of quality of life impairment recorded in a wide range of skin diseases (8).

## **Strategies for improving quality of life in people with skin disease.**

The “Six Star Strategy” for improving quality of life in people with skin disease is based on:

- \*1. The clinician being informed.
- \*2. Targeting the most affected patients.
- \*3. Evidence based therapy, including QoL evidence, being available.
- \*4. Enhancing adherence to therapy.
- \*5. Providing appropriate support to patient and to “the Greater Patient” i.e. the partner and other family members.
- \*6. Monitoring of QoL to demonstrate success or failure of intervention.

## **Conclusion**

In the 21<sup>st</sup> century the speciality of Dermatology has moved from being “doctor-centred” to being “patient-centred”. A crucial aspect of this maturing of our clinical speciality has been the realisation that the impact of the disease on the patient is a matter which is not only worthy of our attention, but which it is our responsibility to address. The development of measurement techniques, which are continuing to evolve, has contributed to this transformation. Measurement has opened the door to greater understanding of the patient, more appropriate clinical decisions, and ultimately improved quality of care.

## **Further information**

Further information about many of the quality of life measures mentioned above, including versions for download for routine clinical use and including translations, is given at [www.dermatology.org.uk](http://www.dermatology.org.uk)

## **Conflict of interest**

AYF is joint copyright owner of the PDI, DLQI, CDLQI, FDLQI, IDQoL, DFI, CADI and PFI questionnaires.

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