



EUROPEAN ACADEMY OF
DERMATOLOGY AND VENEREOLOGY

Information Leaflet for Patients

QUALITY OF LIFE MEASUREMENT: WHY IT MAY HELP YOUR SKIN PROBLEM

The aim of this leaflet

This leaflet is designed to help you understand more about quality of life measurement in the context of skin disease, the importance of measuring it, and what improved quality of life means.

QUALITY OF LIFE MEASUREMENT: WHY IT MAY HELP YOUR SKIN PROBLEM

How can skin diseases affect your quality of life?

Skin diseases can cause many different problems that make life difficult. Fortunately, many people aren't badly bothered by them, but skin diseases can cause itch, pain, or other discomfort, and they can prevent you from doing things. They may interfere with social activities, meeting people, doing sports, or having close relationships. They can make it difficult to work or study, or even to go shopping or do housework. Sleep can also be affected.

Rarely, skin disease can be so bad that people have to be hospitalized, and some types of skin cancer can even cause early death. The impact on daily life is a common reason for people to seek help for their skin disease.

Why is it helpful to measure quality of life?

Doctors and nurses caring for people with skin diseases often don't realise how badly the lives of these people are being affected. If they knew, they might offer different treatments or give extra help and advice. Years ago, the only way to measure skin disease was to measure, for example, the amount of scaling or redness. But now, measuring quality of life focusses on the patient, not just the skin condition.

Measuring quality of life is helpful for the following reasons:

1. If quality of life were measured, then it would be possible to see whether this was getting better or worse, and also to help decide what treatment would be best.
2. Measuring quality of life may help the process of shared decision-making between the patient and the clinician, and in setting goals together for treatment.
3. Using the measures may also improve the relationship between patients and their clinicians.
4. The measures can also occasionally be useful in prompting or guiding the clinician to seek extra help by referring patients to other specialists.

How can quality of life be measured?

It is fairly easy to measure quality of life. Its measurement requires completion of a questionnaire. Usually the questions are appropriate as the questionnaires are based on reports directly from patients. The answers give an overall score, which makes it clear to the clinician how badly you are affected by the skin disease.

There are various types of questionnaires to measure quality of life. Some have questions specific to one condition, and others can be used by people with a wide range of skin diseases. Examples of these are the DLQI (Dermatology Life Quality Index) or Skindex.

Because the lives of infants, children, teenagers, and adults can be very different, there are different questionnaires aimed at varied age groups. For example, there is a Children's Dermatology Life Quality Index (CDLQI).

Do I have to fill out these questionnaires?

You don't have to fill out these questionnaires, as this is up to you. But if asked, it may be helpful for you to do so, as it may help your clinician make better decisions about your treatment. In many countries, there are guidelines to assist your clinician about therapy. One reason why your clinician asks you to fill out a questionnaire is that some of these national guidelines recommend measuring quality of life before and during treatment.

How long does it take?

Most of the quality of life questionnaires that are used in the clinic are short and take only two or three minutes to complete. There are longer ones that are sometimes used for research.

What difference will this make for my skin problem?

Of course, just completing a questionnaire makes no difference in itself. But the information that this gives your clinician may be very helpful in guiding your clinician to give you the best possible treatment.

Where can I get these questionnaires?

Usually your dermatologist will be able to give you a quality of life questionnaire. It is available on paper and sometimes also on “apps.” You can find the DLQI, CDLQI, and other questionnaires online at www.cardiff.ac.uk/medicine/resources/quality-of-life-questionnaires.

How will my quality of life be improved?

The most important thing is to get your skin condition well-controlled or, if possible, cured. So it is essential to take or apply the treatment that you have agreed upon with your clinician, every day.

As your skin gets better, your quality of life will also gradually improve. You should be able to do things or have confidence to take part in things that you previously may have avoided. Sometimes people are able to get back to work, and to develop better relationships with their partner, friends, and family. ■

