Quality of life Measurements in Dermatologic Practice

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PREAMBLE

Health is seen by the public health community as a multidimensional construct that includes physical, mental, and social domains.

Measures of health outcomes now assess:

- saving lives
- improving the quality of life

Goals of medical care includes the cure of disease, avoidance of premature death, mmaintenance or improvement in function, pprolongation of life, relief of suffering, maintenance of quality of life, staying in control, ensuring a good death where this is inevitable and support for family

In the course of a patients illness,

- Multiple goals often apply simultaneously
- Some may be contradictory
- Some may take priority over others
- Shift in the focus of care is an expected part in the continuum of medical care

QUALITY OF LIFE

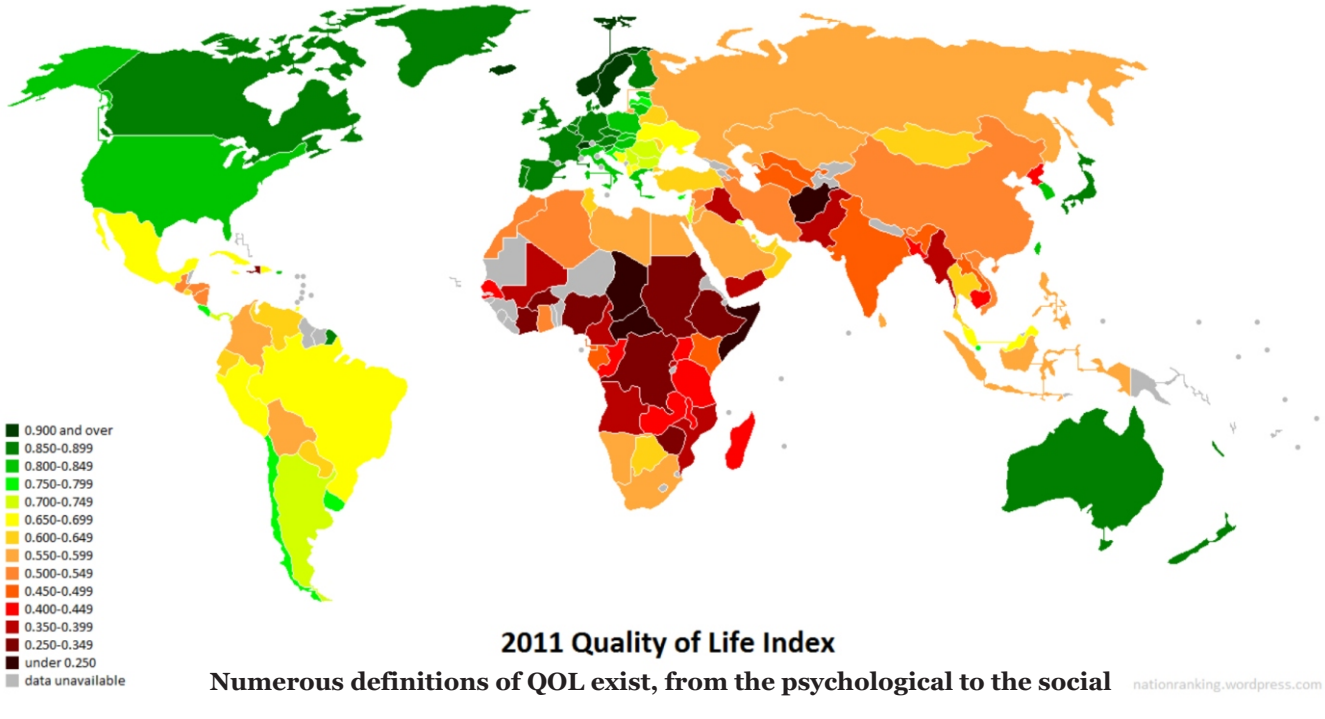
The term ***quality of life*** (**QOL**) references the general **well-being** of individuals and societies. It is the **contentment with everyday life:** the degree of enjoyment and satisfaction experienced in everyday life as opposed to financial or material well-being

The term is used in a wide range of contexts, including the fields of international development, healthcare, and politics.

In general, QOL can be understood as a patient's ability to function in a manner commensurate with his needs, desires, and abilities.

Although all traditional definitions help us approach a "sense" of QOL, none can globally capture what it is for all people.QOL can be defined only by each individual.

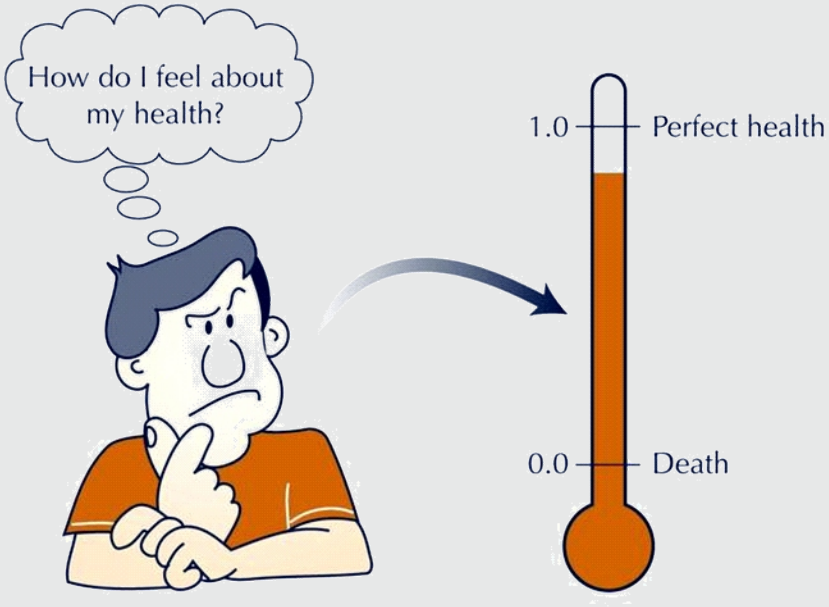
Quality of life should not be confused with the concept of **standard of living,** which is based primarily on income. Standard indicators of the quality of life include:



Numerous definitions of QOL exist, from the psychological to the social

- wealth
- Employment
- Built environment
- Physical and mental health
- Education
- Recreation and leisure time
- Social belonging

The domains of QOL are; Sense of Well-being and Self satisfaction, Physical state, Emotional state, Intellectual functioning, Work performance and Social participation



MEASURING QOL

Measuring QOL is an inexact science fraught with misinterpretation, over interpretation, and biased or inadequate questioning. However, the science of QOL evaluation has progressed to such an extent that dependable and reproducible results that allow investigators to estimate a patient's QOL are achievable.

For the purposes of decision algorithms and models, QOL measurement must be reported numerically, on a scale from 0 to 1:

- 0 represents "death" and
- 1 represents "perfect health."

The value of a utility is that all health states can be placed in this common scale.

HEALTH-RELATED QUALITY OF LIFE (HRQL)

The concept of health-related quality of life (HRQOL) and its determinants have evolved since the 1980s to encompass those aspects of overall quality of life that can be clearly shown to affect health—either physical or mental. On the individual level, this includes physical and mental health perceptions and their correlates—including health risks and conditions, functional status, social support, and socioeconomic status. On the community level, HRQOL includes resources, conditions, policies, and practices that influence a population's health perceptions and functional status.

Health-related quality of life (HRQL) reflects patients' evaluation of the impact of disease and treatment on their physical, psychological, and social functioning and wellbeing. HRQL is an aid for clinical decision making, monitoring the therapeutic process, communicating with the patient, and evaluating treatment outcome. A good understanding of the concept of HRQL and a correct interpretation of HRQL scores are essential.

Health-related QoL (HRQoL)

Generic methods have been constructed for general use to compare data between different diseases including skin disorders. They are commonly described as QoL questionnaires. Many of these only measure physical symptoms, and are therefore more appropriately termed health-related QoL (HRQoL) methods.

SKIN DISEASES

Quantification of disease impact or morbidity in many skin diseases is complicated by lack of the 'hard' endpoint customarily used in biomedical studies, i.e. Death

Quantification of QoL is particularly important because it provides additional information to the traditional objective clinical scoring systems. Understanding actual morbidity makes it possible to achieve the free flow of relevant information for diagnosis and prescription, as well as subsequent adherence to therapy.

Skin diseases are a common health condition responsible for considerable disability. Patients with skin disease may experience severe symptoms, such as itching, pain, and discomfort that can have a profound psychological impact. Furthermore, patients' social and physical activities, including sports and work, may be adversely affected because of reluctance to allow others to see their skin disease. Some treatment modalities can situationally decrease quality of life (QoL) due to the difficulties involved in using topical creams and ointments.

Skin disease adversely affects the quality of life (QOL) of patients. Measurement of this impact is required for

- clinical and health service research
- clinical practice
- evaluation of new drug therapy

Virtually all aspects of patient's 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.

Severe symptoms 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. Skin diseases can have a major impact on patients' lives in terms of psychological well-being, social functioning and everyday activities. Assessment of patients' quality of life has become an important endpoint in clinical trials in addition to the traditional clinical outcomes

Despite the availability of a variety of instruments and new psychometric techniques, there is no consensus as to which HRQOL instruments are to be preferred in dermatology

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

DISEASE SPECIFIC MEASURES

- ¢ Psoriasis Disability Index (PDI)
- ¢ Cardiff Acne Disability Index (CADI)
- ¢ Acne-Specific Quality of Life Questionnaire (Acne-QoL)
- ¢ Infant's Dermatitis Quality of Life index (IDQOL)
- ¢ Psoriasis Quality of Life index (PSORIQoL)

DERMATOLOGY SPECIFIC MEASURES

There are also Dermatology specific measures which could be used across all skin diseases. Examples include, Dermatology Life Quality Index (DLQI), Dermatology Quality of Life Scales (DQoLS), Skindex

SKINDEX

The Skindex is an instrument that measures the effects of a skin disease on a patient's QoL, It is a self-administered questionnaire that was originally created in English. It initially included 61 questions but was then modified to 29 questions. Later, a 16-question short questionnaire, known as the Skindex-16, was introduced. The Skindex-16 assesses the domains considered to be essential in any QoL assessment instrument, such as burden of symptoms, social function, and emotional state. The Skindex-16 has advantages over the Skindex-29, in that it is a brief, single-page version with fewer items, and measures the inconvenience rather than frequency of a patient's experiences.

CHILDREN AND FAMILIES

Skin disease can be very disruptive to the lives of children. There are even more problems in trying to measure QoL in children than in adults

Measuring the impact of atopic dermatitis on the families of affected children (the Dermatitis Family Impact (DFI) questionnaire), Children's Dermatology Life Quality Index (CDLQI)[28] has been described and is widely used.

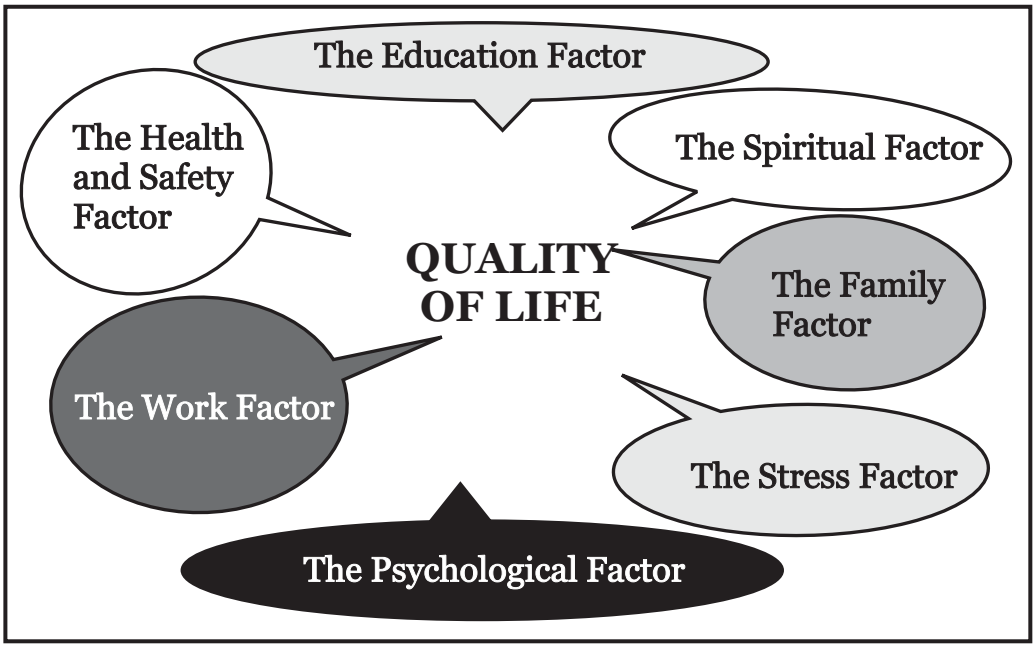
Patients with skin diseases experience a wide range of symptoms which affect their lives, ranging from trivial problems to major handicaps. Sometimes these symptoms are caused by objective changes that impair daily life directly and measurably, while at other times the impairment is subtler and occurs mainly on a psychological level. An understanding of the impact of disease is necessary in the management of patients.

If patients with chronic disorders fail to cope with their disease and the threat that follows, emotional maladjustment characterized by anxiety and depression may develop. This is very relevant for dermatological patients

USES OF QOL MEASUREMENTS

Assessment of QoL is needed not only in clinical practice, but also in decisions concerning healthcare resource allocation where dermatology often fares badly due to a lack of understanding of the major adverse effects of skin disease. Although not life-threatening, many skin diseases are likely to have psychological and social implications for the patient. Information from the use of appropriate measures may

help overcome this problem



MEASUREMENT OF QOL IN SKIN DISEASE

A range of methods has been described to measure the impact of skin disease. These methods include:

(I) Generic instruments (methods) such as the SF-36 (36-item Short-Form Health Survey)

(ii) Specialty-specific questionnaires such as Dermatology Life Quality Index (DLQI) or SKINDEX,

(iii) Disease-specific methods such as Quality of Life Index for Atopic Dermatitis

(iv) Utility methods such as time trade-off method or time spent on treatment

Disease-specific questionnaires are often more sensitive than HRQoL, are of particular relevance in dermatology, where physical impairment may be minimal.

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