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Review Article

Quality of life issues and new benchmarks in the assessment of skin diseases

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Abstract

With the enhanced awareness about the importance of conducting outcome research, it has become apparent to the dermatologists that it is important to develop a quality of life scale that is reliable, sensitive and validated. However, in venturing into this new field, it is important to recognize that there are issues relatively unique to the assessment of skin patients as compared to the assessment of other medical conditions, such as hypertension or cardiac disease.

First, the traditional outcome measures used in most areas of medicine such as survival data or measurable changes in laboratory values, are most often not available to assess the outcome among dermatology patients because the threat of death is rare in dermatology practice and also many common skin conditions such as psoriasis or eczema do not have easily measurable laboratory data to document the status of the disease. On the other hand, patients with skin disorders can be greatly affected by disfigurement because the skin diseases are frequently visible to others and the patient's quality of life may be devastated due to his or her body image or the reaction of others to his or her disfigurement. In other words, as we venture into this new field of assessing quality of life issues in skin disease patients, scientifically and quantitatively, understanding the underlying philosophical and conceptual issues involved is very important.

This article encompasses these issues and advantages of quality of life assessment and the various questionnaires used for this purpose. In the end, a few studies conducted at King Edward Medical College, Lahore are presented.

Key words
Quality of life, DLQI.

Introduction

The concept of health-related quality of life (HRQoL) is gradually expanding in both scope and importance in medical care. Basically, it consists of a constellation of information about an individual's physical, social and psychological well-being. It also defines treatment effectiveness by focusing on the ability of an individual to lead a productive and enjoyable life. HRQoL also describes the burden of disease in terms of importance of the patient's day-to-day life as well as the burden to society.

Philosophical and conceptual issues

Quality of life (QoL) is a somewhat vague and abstract term. To be able to assess quality of life quantitatively and scientifically, it is important to define all the relevant parameters defining the term. In defining "quality of life", it is important to make the assessment as comprehensive as possible, encompassing the psychological, social

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and occupational impact of disease as well as the physical impact. For a great majority of dermatological patients, the most important negative impacts on quality of life are appearance related. Skin disorders rarely cause a total physical disability, but they frequently disfigure the patients. Ultimately, the psychosocial and occupational consequence of disfigurement is much more relevant for the dermatological patients than are the pure physical limitations.

Therefore, in order to assess the full impact of skin disorders on a person's quality of life, it is important to consider at least these four different aspects: physical, psychological, social and occupational impact.[1]

Physical impact The physical impact has two subcomponents, namely, physical symptoms and physical (functional) limitations. Physical symptoms refer to the presence and intensity of symptoms such as itching, irritation, pain etc. Functional limitations refer to observable, objective limitations on the part of the patient, such as inability to use the hands or ambulate due to the presence of a painful skin condition on palms and soles.

Psychological impact Psychological impact refers to purely subjective, philosophical factors such as the impact of skin disease on the self-esteem and body image, as well as the presence or absence of various subjective symptoms such as depression, anxiety, anger, embarrassment, self-consciousness etc. which can compromise the patient's quality of life, even if nobody else seems to notice the presence of this intra-psychic distress in the patient.

Social impact Social impact refers to the impact a skin disorder has on social functions such as courtship, sexual relationships, relationship with family members etc.

Occupational impact Finally, occupational impact refers to the impact of skin disease on the types of occupation the patient can engage in, promotion or rejections in the workplace etc.

For each of these aspects, one can assess the patient's purely subjective discomfort and the objective assessment of how the skin disease actually prevented the patient from participating in various activities.

Advantages of QoL assessment

Dermatological diseases have sometimes been discounted in their severity as being "only skin condition" but as health care management and patient expectation shift towards efficacy, comparison of treatment approaches and efficiency measurements of health outcome, our concepts regarding life quality and the economic impact of skin diseases are changing. The various groups of people who can gain advantages by making QoL assessments in dermatological conditions include:

- Clinicians
- Patients
- Industry
- Health care managers

Uses by clinicians

QoL and economic evaluation of therapeutic interventions can be utilized in developing algorithms or step ladder approaches as starting points for individual patients. Also the choice of an effective therapy for our patients would be more precise if we have gathered enough information about the magnitude of improvement in life quality and response of various groups to different therapies.

Uses by patients

The information on QoL can be used to educate those afflicted by a given disease and their caregivers. This can also help patients realize that the health providers are truly involved in the whole disease process.

Uses by the industry

a. The pharmaceutical/ medical device industry

To aid in differentiation of products for selected patient population, it is helpful to have documentations of the impact of treatments on various issues such as compliance of dosage vs. lifestyle, duration of treatment and number & cost of follow-up visits and laboratory monitoring, comparison of generic vs. brand name products etc.

b. The cosmetic/ consumer product industry

By being aware of the QoL and economics of skin disease and their care, manufacturers of over-the-counter products gain insight into advantages of helping to prevent skin diseases e.g. by reformulating products so that they contain sunscreen or are less likely to irritate eczema-prone skin, or non-comedogenic cosmetics for patients with acne.

Uses by health care providers and managers care organizations

The database of QoL can help these organizations in making their various decisions e.g. cost containment and disease-severity indices.

Methods of QoL assessment

The methods of QoL measurement can be broadly divided into three groups:

- General measures
- Disease specific measures
- Dermatology specific measures

General measures

The use of general health measures is essential in order to draw any comparison between the impact of skin disease and other non-skin diseases on patients' lives. These include SF-36, Euoqol, Sickness Impact Profile and Patient Generated Index.

SF-36 (Short Form – 36)

It has been the most widely used HRQoL instrument for measuring health status. It consists of 36 items which cover eight domains namely physical functioning, body pain, role limitation due to physical health, restrictions caused by personal or emotional problems, emotional well being, social functioning, energy/ fatigue and general health perceptions. Additionally, one item indicates perceived change in health.

Sickness impact profile

It was developed in the 1970s as a measure of perceived health status. It consists of 136 health-related statements grouped into 12 areas of daily living.

Patient generated index

It can be used in any medical condition and was designed to measure the effects on their lives that patients themselves consider the most important.

Although these older questionnaires have been most valuable during the development of the science of QoL measurements, but the problem with their use is that many of the questions are irrelevant and suitable new instruments are already available to researchers.

Dermatology-Specific Measures

- Dermatology Life Quality Index
- Dermatology Quality of Life Scales (DQoLS)
- SKINDEX
- Dermatology-specific Quality of Life instrument

Latest additions:

- Infant's Dermatitis Quality of Life Index (IDQoL)
- Children Dermatology Life Quality Index (CDLQI).

SKINDEX

The SKINDEX is a 62-item self-administered study instrument designed to assess skin disease HRQoL that has had reliability and responsiveness validation.

Dermatology Life Quality Index

The DLQI was the first dermatology-specific, health-related, quality of life questionnaire published. It shows high specificity, repeatability and internal consistency scores.[2]

Children's Dermatology Life Quality Index

The cartoon and text version of the CDLQI is equivalent to the previously validated text-only CDLQI version but is faster and easier to use and is preferred by children and parents.

Table 1 Cardiff Acne Disability Index (CADI).

1. As a result of having acne, during the last month have you been aggressive, frustrated or embarrassed?
2. Has having acne during the last month interfered with your daily social life, social events or relationships with members of the opposite sex?
3. During the last month have you avoided public changing facilities or wearing swimming costumes because of your acne?
4. How would you describe your feelings about the appearance of your skin over the last month?
5. Please indicate how bad you think your acne is now.

Table 2 Dermatitis Family Impact Questionnaire

Over the last week, how much effect has your child having eczema had on:

1. Housework, e.g. washing, cleaning.
2. Food preparation and feeding.
3. The sleep of others in family.
4. Family leisure activities, e.g., swimming.
5. Time spent on shopping for the family.
6. Your expenditure, e.g. costs related to treatment, clothes etc.
7. Causing tiredness or exhaustion in your child's parents/carers.
8. Causing emotional distress such as depression, frustration or guilt in your child's parents/carers.
9. Relationships between the main carer and partner or between the main carer and other children in the family.
10. Helping with your child's treatment had on the main carer's life.

Disease specific measures

- SCORAD
- Psoriasis Disability Index (PDI)
- Cardiff Acne Disability Index (CADI) [**Table 1**].
- Acne-specific Quality of Life (Acne-QoL)

Latest additions:

- Psoriasis Quality of Life Index (PSORIQoL)
- Dermatitis Family Impact Questionnaire (**Table 2**)

SCORAD

The European Task Force of Atopic Dermatitis has this scoring index for their target disease combining extent, severity and subjective symptoms.

Psoriasis Disability Index (PDI)

There is now twenty years experience with PDI. It consists of 15 questions and has been used in over 20 countries in more than 13 languages.

Research on QoL conducted at King Edward Medical College/ Mayo Hospital, Lahore-Pakistan

Under this heading, a few studies are presented which were conducted at the Department of Dermatology, King Edward Medical College/ Mayo Hospital, Lahore over the past few years. A variety of different scales were used in these studies. These are described briefly:

Study No. 1: anxiety and depression in patients with acne vulgaris: Hospital Anxiety & Depression Scale (HADS)[3]

This scale has an established psychiatric validity and facilitates calculation of psychiatric caseness. The scores were interpreted as < 8=no clinical problem, 8-10=mildly disturbed individuals, 11-21=clinically significant anxiety/ depression. A total of 100 patients, 48 males and 52 females, with mean age 20 years and mean duration of 31 months were enrolled. It was concluded that acne causes psychological disability, the severity of which can be detected using simple questionnaire. Personality influenced the individual perception of disability and was independent of severity of the disease.

Study No. 2: Psychological disabilities in patients with port-wine stain[4]

In this study, two questionnaires were used; the Dermatology Life Quality Index (DLQI) and the Direct Questionnaire which consisted of 11 questions with a yes/ no format. There were 30 patients in this study, 27 females and 3 males. Twenty nine were single and only one was married. Their DLQI score ranged from 0-17 and the mean score was 5.36. The result of the direct questionnaire is depicted in **Table 3**.

Study No. 3: Quality of life (QoL) in vitiligo patients[5]

A total of 100 patients, 48 males and 52 females were included in this study. Their mean DLQI score was 9.56 (31.86%) and ranged from 0-29. The score in males was 8.17 (± 5.55) and 10.85 (± 4.76) in females. It was concluded at the end of this study that impairment of QoL is greater in females with disease on exposed parts and the patterns of handicap included greater psychological distress, avoidance of social interactions with minimal impact on physical activities.

Study No. 4: Effect of itraconazole pulse therapy on QoL in disto-lateral onychomycosis[6]

The questionnaire used was disease specific and consisted of fifteen questions covering multiple domains. Graded scoring was done. The more the score, the worse was the quality of life. A total of 62 patients were enrolled, 47 males and 15 females. Finger nails were involved in 46 patients and toe nails in 16 patients. It was concluded at the end of this study that itraconazole pulse therapy improves the QoL in disto-lateral subungual onychomycosis. The disease causes greater psychological distress with avoidance of social interactions and minimal impact on physical activities.

Table 3 Result to Direct questionnaire in patients with port-wine stain.

Question	%
1. I feel people stare at me because of my birthmark	80
2. I have been hurt by what other people say because of my birthmark	70
3. I feel the need to hide my birthmark	66
4. My birthmark has affected my self-confidence	66
5. Having a birthmark makes me feel different from other people	66
6. I am resentful of people with normal skin	53
7. I feel physically unattractive & sexually undesirable because of my of my birthmark	43
8. If my child were to have a birthmark, I would feel guilty	36
If my birthmark were improved by treatment, I would feel	
9. Better about myself	97
More comfortable with people of the same sex	90
11. More comfortable with members of the opposite sex	80

Study No. 5: Effect of contact dermatitis on dermatology life quality index[7]

The Dermatology Life Quality Index was used in this study which consisted of ten questions pertaining to various aspects of the patients' life. A total of 87 patients were enrolled. There were 27 males and 60 females. The duration of their disease ranged from 2 weeks-25 years. The mean DLQI score was 11.29 ± 6.8 (range 1-30). The mean score in male patients was 9.48 ± 5.36 and 12.1 ± 7.31 in females. It was concluded at the end of this study that impairment of QoL is greater in married females, 21-40 years age group, pompholyx & discoid eczema patterns of handicap both physical and psychological.

Conclusion

QoL assessment is an important outcome variable in dermatology research. A few of many areas where these tools are being developed include: i. Diseases, e.g. skin malignancy, urticaria, melasma, pityriasis rosea, STDs, aging skin. ii. Investigations e.g., patch testing, molecular and genetic studies iii. Therapies e.g. the cost effectiveness of using foams instead of lotions, gene therapy, laser therapy, newer drugs like alefacept, infliximab. It may not be an understatement to conclude that quality of life and skin health are essential components for the future of dermatology.

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