Quality of Life in Dermatology

Natasa Teovska Mitrevska*

International Balkan University, Skopje, North Macedonia Remedika General Hospital, Dermatology Department, Skopje, North Macedonia

Abstract

Quality of life (QoL), as defined by the World Health Organization, includes individuals' perceptions of their life circumstances within their cultural and value systems including their goals, expectations, standards, and concerns.

Evaluating QoL is important for understanding the nonclinical aspects of diseases, identifying functional and psychological limitations, and choosing treatment during the early stage of the disease. It also contributes to improve the doctor–patient relationship.

The skin, being the interface with the environment, serves as a means of

communication. Skin diseases can also affect self-image and social relationships, especially during vulnerable stages like childhood and adolescence.

Dermatologic conditions often affect patients physically, emotionally, and functionally. Identifying the impact of skin conditions, quantifying the burden, and using this information to improve patients' well-being are important objectives in clinical dermatology. Various scales and indices have been developed to measure QoL in children and adolescents with skin diseases. QoL is particularly important in dermatology due to the field's focus on improving skin-related

Address for correspondence: Natasa Teovska Mitrevska*, International Balkan University, Skopje, North Macedonia; Remedika General Hospital, Dermatology Department, Skopje, North Macedonia. Email: nteovska@remedika.com.mk

QoL. Skin conditions often manifest in a multidimensional picture, affecting emotional states, social interaction, symptoms, and functional impairment. Quantifying the quality-of-life impact of skin conditions is a relatively recent effort, emerging from the movement across medical science to inform intervention outcomes.

Key words: Quality of life, holistic, measure, skin disease, scales, outcomes

INTRODUCTION

The World Health Organization (WHO) Working Group defines quality of life as the personal evaluation of functioning based on individual and/or cultural standards, values, expectations and goals. This definition highlights quality of life as a multidimensional index shaped by subjective evaluation within cultural, social and environmental context (1). Quality of life comprises both objective and subjective dimension, each representing seven domains: health, material well-being, productivity, intimacy, safety, society, and emotional wellbeing. Objective domains include culturally relevant measures of well-being while subjective domains emphasize individual satisfaction weighted by importance.

Despite its widespread use, the concept of quality of life lacks consistency, with over 100 definitions cited in the literature, according to Robert A. Cummins (2).

1. The use of the instruments of WHOQL

The World Health Organization (WHO) developed a quality-of-life instrument called WHOQOL through its WHOQOL Group with fifteen international field centers (1). This assessment aims to be utilized:

a) In medical practice

In clinical practice, the WHOQL instruments can be used in other forms of assessment, providing valuable information that can indicate areas of impact and guiding treatment decisions. In addition, they can be used to measure changes in quality of life during treatment.

b) Improving the doctor-patient relationship

By enhancing physician's understanding of how diseases affect patient's quality of life, interactions between patients and physicians improve. This leads to more fulfilling healthcare experiences and comprehensive medical care provided (2,3).

c) Assessing the effectiveness and relative merits of different treatments

WHOQL instruments contribute to treatment assessment, providing a comprehensive understanding of treatment impacts and outcomes (1,3).

d) Assessing health services

In the periodic review of the completeness and quality of medical services, the concerns of patients are important. These instruments provide additional assessment of health services, by measuring the relationship between the health service and patients' quality of life, and also by directly presenting a measure of patients' perceptions of the quality and availability of health care.

e) In research

WHOQOL instruments provide insights into the nature of illness and their effects on person's subjective well-being across various domains (1).

f) In policy creation

When healthcare providers implement new policies, it is important to assess the effects of these policy changes on the quality of life of individuals who interact with healthcare services.g) Educating the public about quality

Educating the public (patients) on quality issues promotes self-protection, facilitates convenient access to healthcare services and raises awareness about quality and health. The growing awareness

of quality of life extends beyond patients to all healthcare service users (3).

2. Quality of life in dermatological conditions

Skin diseases affect various aspects of patients' lives and successful treatment can significantly improve their quality of life (QoL). Over the past 20 years, the number of publications on QoL in dermatology has constantly grown. Multiple dermatology-specific and disease-specific QoL instruments of different quality have been developed and used in research.

Many national and international guidelines recommend QoL assessment in dermatology and some of them contain detailed recommendations on treatment goals and approaches based on the DLQI (Dermatology Life Quality Index) score banding and minimal clinically important difference (4,5).

Currently, numerous standardized questionnaires exist for determining quality of life in dermatological conditions. While these questionnaires are necessarily used in clinical studies examining certain drugs in the treatment of dermatological diseases, they are rarely used in daily routine practice due to lack of time and limited knowledge of questionnaire evaluation. In dermatology, QL can be assessed using generic instruments (applicable to a wide variety of conditions that allow comparisons between diseases), dermatology-specific instruments (applicable to all skin diseases and allow comparisons between skin diseases), and condition-specific instruments (use is limited to specific skin disease and possible only comparisons between groups of patients with the same skin condition) (6).

The creation of the Dermatology Life Quality Index (DLQI) questionnaire by Finlay and Khan in 1994 facilitated many studies on the impact of skin diseases on patients' QoL (6).

DLQI -dermatology quality of life index was the first dermatology-specific tool for assessing skinrelated QL. It was designed as a "simple practical measure for routine clinical practice (3). Until now, the DLQI is the most commonly used QL instrument in dermatology and is used in most QL studies in patients with skin diseases. The DLQI questionnaire has been translated into 55 languages and is extensively validated (6,7).

Many skin diseases such as psoriasis, atopic dermatitis, acne vulgaris, vascular malformation, vitiligo, scars, negatively impact patient's lives and can also impact their families significantly, comparable to nondermatological conditions (7,8,9).

Some skin diseases come with physical symptoms like itching and pain, which affect daily activities such as sleep, rest, and intimate intercourse.

The severity of physical symptoms is an important clinical aspect of disability that can lead psychological distress in dermatological patients. Itch and fatigue, reported by more than 50% of patients, are among the symptoms affecting the quality of life. Different physical symptoms including itching, irritation, and burning, were prevalent in patients with psoriasis and with concurrent psychological distress (7,8,9,10).

Higher levels of fatigue are associated with psychological distress in patients with psoriasis and atopic dermatitis (11,12,13). Adolescent patients with acne vulgaris often experience

low self-esteem, social isolation, depression, and suicidal thoughts (14,15,16). Parents report sleep disturbances, frustration, and irritability in their children with Atopic Dermatitis (AD). Studies have found a correlation between AD and attention-deficit/ hyperactivity disorder (17,18). Infants with AD are also found to be at greater risk for the development of mental health problems by the age of 10. Children can have decreased self-esteem and significantly reduced psychosocial functioning. Children and adolescents with psoriasis are more likely to experience anxiety, depression, decreased sexual intimacy, joint pain, chronic itching, and decreased perception of social connectivity (19, 20).

People with dark skin color often face stigma (21,22). The quality of life (QoL) of patients with vitiligo is directly related on clothing choices, camouflage use, the avoidance of work activities,

and the appearance of negative reactions from others (21). Some studies indicate psychiatric comorbidity in vitiligo, with a prevalence between 25% and 35% (6,23). Despite no direct physical damage, vitiligo causes an important psychosocial burden. According to several authors, patients with vitiligo suffer from a false self-image, low self-esteem and experience a high level of disability from their skin disease (23).

However, others authors argue that many vitiligo patients feel distressed and stigmatized by their condition, especially in social activities (24). It is also believed to cause anxiety and shame, which may negatively impact intimate relationships (25).

Emotion regulation is also related to quality of life in skin diseases. Previous studies suggested a strong association between skin diseases and emotion dysregulation. Research has demonstrated a possible association between psychological distress and the onset, recurrence, and severity of psoriasis (26,27,28).

Family members are involved in the disease's impact, whether by ignoring it, creating a taboo around the disease itself, or providing great care. The relationships, hobbies (e.g sea trips, socializing, excursions), daily activities (diet, organization, and cleaning), financial structure, sleep and emotional state of the family members change (6,29). Therefore, when assessing the patient's quality of life, the impact of the disease on the quality of life of the entire family have to be taken into account (29,30).

QoL is particularly important in dermatology because a primary aim of dermatology is to improve QoL in relation to the skin conditions. While some dermatologic conditions such as melanoma, cutaneous T-cell lymphomas, and Merkel cell carcinomas can affect survival, most dermatologic conditions do not shorten life expectancy (31,32). The majority of conditions affect dermatologic patients physically, emotionally, or functionally (33). CONCLUSION

Identifying how skin conditions affect lives, quantifying this burden, and using the information to improve patients' lives individually are important goals in clinical dermatology. (33, 34)

Acknowledgements: None declared.

Conflict of Interest Statement: The author declares that have no conflict of interest.

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