Assessing Quality of Life in Older Adult Patients with Skin Disorders

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Abstract

Older adults experience a number of skin diseases and age-related changes that substantially affect quality of life. This review of available literature briefly describes skin conditions associated with aging that affect the skin’s appearance (e.g., age spots, wrinkles, and prominent veins), function (e.g., decreases in skin barrier function, mechanical protection, sensory perception, wound-healing capability), and structure (e.g., dryness, roughness, and skin laxity). Summaries are provided for a number of quality of life instruments that can be used for adult dermatology patients to assess the effects of treatment and disease progression, perceptions of well-being, and the value that patients place on their dermatologic state of health. These include instruments assessing the effect of dermatology on overall health-related quality of life (e.g., Dermatology Life Quality Index, Family Dermatology Life Quality Index, and Skindex), an instrument assessing the impact on health-related quality of life of various consumer products (the Farage Quality of Life Questionnaire), and condition-specific measures (e.g., the Quality of Life Index for Atopic Dermatitis, Charing Cross Venous Ulcer Questionnaire, Pressure Ulcer Quality of Life, Psoriasis Disability Index, and Rosacea-Specific Quality of Life). Although a number of such validated dermatology-related instruments are available, an opportunity exists for developing and validating health-related quality of life measures specifically for older patients and the dermatologic conditions most pertinent to them.

Introduction

What Is Health-Related Quality of Life?

Quality of life (QoL) is a broad concept that can touch on many aspects of life, including fulfillment of basic needs, social and emotional well-being, and physical well-being [1]. Health-related quality of life (HRQoL) is a subset of the broad definition of QoL and has become an important component of health surveillance. Self-assessed health status has proven to be a powerful predictor of mortality and morbidity [2]. While HRQoL instruments tend to focus on perceived physical and mental health and function, they are intimately connected to the broader aspects of life. To paraphrase the World Health Organization, health is not merely the absence of disease, it is the state of complete physical, mental, and social well-being [1].

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Why Is It Important to Measure Health-Related Quality of Life?

Patient’s histories, clinical examination, and diagnostic testing provide information about patients’ health and the progression (or regression) of disease. Assessments of HRQoL provide a measure of the integration of the disease and its treatment into daily living and the ability of a person to lead an enjoyable and productive life [3]. Further, it involves patients in their care by allowing them to express their opinions about the value they place on health and how their illness and its treatment affect them (Fig. 1). For patients with chronic illness, HRQoL assessment measures the changes in their well-being throughout the course of the disease. At the community level, HRQoL enables health agencies to address broader areas of public policy pertaining to health-care providers and social services [2].

How to Measure Quality of Life?

QoL is at once a simple yet complex paradigm, with philosophers, sociologists, psychologists, economists, theologians, clinicians, and lay persons all having different conceptualizations [4–7]. While a consensus exists that HRQoL is important to patient care, there is no absolute agreement among researchers on how to assess either HRQoL or QoL in general [8]. Nevertheless, two fundamentally different approaches are commonly applied: (1) health status measurement and (2) utility/value/preference assessment.

Health status measures assess various domains of a person’s physical, physiological, or mental health. Health status measures can be either generic (applicable to any disease or health state) or disease-specific (applicable to a single condition or disease) [8]. One of the most commonly used generic health status...
instruments is the SF-12 Health Survey, a 12-item measure encompassing eight domains: physical functioning, social functioning, mental health, role limitations due to physical problems, role limitations due to emotional problems, vitality (energy and fatigue), pain, and general health perceptions. Each domain is scored separately from 0 (worst) to 100 (best), and Physical Component Summary and Mental Component Summary scores can be calculated [9]. State-of-the-art health status measurement is based on item response theory, which draws from a bank of validated questionnaire items covering the spectrum of a domain of HRQoL, such as depression or fatigue. Item response theory is conducive to computerized HRQoL assessment with but a limited number of questions and to developing short forms of measures [10, 11]. Besides such generic measures, a wide variety of disease-specific measures have been developed. Health status measures specific to dermatology are reviewed in detail later in this chapter.

Utility/value/preference measures of HRQoL, in contrast to health status measures, assess the value or desirability of a state of health against an external metric such as risk, time, or money [8, 12, 13]. The most common instruments used to measure utility/value/preference, hereafter referred to as utility measures, are (1) the standard gamble, (2) time trade-off, and (3) the rating scale. The standard gamble determines the risk of (usually) death that one would be willing to take to improve a state of health. Scores on the standard gamble can range from 0 to 1, where 0 usually represents dead and 1 represents excellent or perfect health. The time trade-off technique asks how many months or years of life one would be willing to give up in exchange for a better health state. The rating scale is not strictly a measure of utility because it does not involve comparison against an external metric. Instead, the rating scale asks the subject to rate his or her health on a scale, e.g., from 0 (dead) to 100 (perfect health). This instrument is the simplest of the three utility measures of HRQoL.

A less common utility measure, known as willingness to pay (WTP), assesses the amount of money, in the form of either cash or insurance premiums, one is willing to pay for a cure [14]. This instrument is particularly germane to nonlife-threatening conditions and, hence, can be applied to many dermatologic diseases.

**Applicability of Health Status Measures and Utility Measures of HRQoL**

Health status or utility measures of HRQoL are applicable to different forms of health monitoring. For example, health status measures can be used (1) to interpret and monitor outcomes in clinical treatment programs, (2) as end points in clinical trials, (3) to monitor population health, and (4) to estimate the burden of different disease conditions. Utility measures are used primarily to calculate quality-adjusted life years in decision and cost-effectiveness analyses. Although not as sensitive to changes in health as health status measures, particularly disease-specific health status measures, utility measures can be used to supplement measures of health status. For example, if a particular therapy in a clinical trial is found to be superior in several aspects of health status, but inferior in others, utility measures could “break the tie” and determine the optimal therapy.

**Direct and Indirect HRQoL Measures**

Health status measures are generally ascertained directly, from either patients, their surrogate decision makers, or their health-care providers. Utility measures can be ascertained directly from either patients, their decision makers, or health-care providers or indirectly by surveying the general population. For example, the direct assessment of utility may involve asking a respondent to make trade-offs between a particular state of health and a hypothetical gamble involving some chance of a better or worse outcome [15]. The indirect assessment of utility involves first assessing the patient’s health status and then mapping a previously derived utility to that particular state of health. The indirectly derived utility measure is obtained by surveying a sample from the general population that has been given descriptions of various health states and asked to assess their value [8]. Examples of indirect utility measures, also
known as health state classification systems, include the EQ-5D [16], the SF-6D [17], the Health Utilities Index [18], and the Quality of Well-Being Scale [19].

Dermatologic Changes in Older People and Their Impact on Health

As the population ages, managing older dermatology patients will become increasingly important [20]. Older adults experience a number of skin diseases and disorders that substantially affect QoL [21]. Chang and colleagues reported that approximately one-quarter of dermatology visits in 2011 at Stanford Hospital and Clinics were by patients aged 65 years or older [22].

The aging process differs among individuals based on genetic variability, the toxicity of by-products of metabolic processes, and the sufficiency of physiologic resources available for somatic maintenance and repair [23]. Guinot and coauthors [23] identified four categories of factors that contribute to the skin aging process: (1) biological (genetically predetermined and unalterable), (2) environmental (e.g., damage from exposure to sunlight, pollutants, and/or nicotine), (3) mechanical (e.g., repetitive muscle movements such as squinting or frowning), and (4) miscellaneous (e.g., sleep patterns, dietary intake, comorbid conditions, and mental health and well-being).

Skin changes associated with aging are readily apparent: thin, dry skin, age spots, wrinkles, prominent veins, etc. Such changes can be classified broadly as either age-related changes or photoaging [24]. Age-related skin changes are further classified as (1) functional or (2) structural. Functional changes include decreases in skin barrier function, mechanical protection, sensory perception, wound-healing capability, immunologic responsiveness, thermoregulation, and vitamin D production [24] (Table 1). Structural changes lead to dryness, roughness, wrinkling, skin laxity, and decreased skin elasticity [22]. Structural changes emerge as the skin becomes progressively thinner during adulthood (Fig. 2) [25].

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Age-related changes in the skin</th>
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<tbody>
<tr>
<td><strong>Physiologic decrement</strong></td>
<td><strong>Clinical consequence(s)</strong></td>
</tr>
<tr>
<td>Barrier function</td>
<td>Increased skin dryness</td>
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<td></td>
<td>Increased itch</td>
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<td></td>
<td>Slower return to full barrier function after perturbation</td>
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<tr>
<td>Cell replacement</td>
<td>Delayed wound healing</td>
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<td></td>
<td>Rougher skin surface</td>
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<tr>
<td>Lipogenesis</td>
<td>Skin thinning due to decreased subcutaneous fat</td>
</tr>
<tr>
<td></td>
<td>Increased skin dryness</td>
</tr>
<tr>
<td>DNA repair</td>
<td>Increased photocarcinogenesis</td>
</tr>
<tr>
<td>Elasticity</td>
<td>Lax skin</td>
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<tr>
<td>Immunologic responsiveness</td>
<td>Chronic low-grade skin infections</td>
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<tr>
<td>Inflammatory responsiveness</td>
<td>Inapparent injuries and infections</td>
</tr>
<tr>
<td>Mechanical protection</td>
<td>Frequent injuries</td>
</tr>
<tr>
<td>Sensory perception</td>
<td>Frequent injuries</td>
</tr>
<tr>
<td>Sweating</td>
<td>Tendency for hypothermia</td>
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<tr>
<td>Thermoregulation (vascular)</td>
<td>Vulnerability to heat and cold</td>
</tr>
<tr>
<td>Vitamin D production</td>
<td>Suboptimal vitamin D stores, osteomalacia, muscle weakness</td>
</tr>
<tr>
<td>Wound healing</td>
<td>Persistent wounds, weak scars</td>
</tr>
</tbody>
</table>

From Chang AL et al. [22] and The Merck Manual of Geriatrics [24]
shape, uneven pigmentation, reduced cutaneous immunity, reduced sebum production, and lower water content causing drier skin, even xerosis [25].

Older adults are more likely to experience skin irritation or dermatologic disease than younger adults. In fact, most persons over the age of 65 have two or more skin diseases/disorders that could require medical treatment [26]. Urinary and fecal incontinence, for example, are common among older people, and because aging skin is vulnerable to prolonged moisture, dermatologic complications associated with incontinence are frequent [27]. Untreated incontinence can lead to incontinence dermatitis, dermatologic infections, intertrigo, vulvar folliculitis, and pruritus ani. Chronic incontinence can produce a continuing cycle of skin damage, irritation, and inflammation.

Skin cancer is also more prevalent among older persons. In recent years, public education about skin cancer prevention has raised awareness about strategies such as using sunscreen and reducing sun exposure. However, people over the age of 65 have greater morbidity and mortality from skin cancer. The National Cancer Institute reported on data collected from 2007 to 2011. During that time, 44.4 % of new cases of melanoma were diagnosed among people aged 65 and over, and 59.3 % of deaths were due to melanoma [28].

**Health-Related Quality of Life Instruments for Skin Diseases**

HRQoL instruments that measure either patients’ health status or the utility and value that patients place on their state of health may be validated for use in particular populations or validated in a wide variety of cultures, regions, and languages. Constructing and validating a new HRQoL instrument entails both qualitative and quantitative methods [3, 29]. HRQoL instruments should be evaluated for validity, reliability, and responsiveness [30, 31].

The validity of a questionnaire refers to whether the questionnaire or survey measures what it intends to measure. Validity can be assessed with regard to content, criterion or predictive ability, and construct. Content validity can be determined qualitatively through literature review, expert reviews, or cognitive interviews in which people are asked to describe and define what individual questions mean to them, as
Criterion validity refers to the extent to which survey items predict or agree with an objective assessment of the particular criterion (e.g., in clinical evaluations, patient reports are compared with physician reports or medical records). Construct validity examines the assumption that items in the survey that are hypothesized to measure the same concept (e.g., two indicators of emotional well-being) do, in fact, agree. Conversely, items hypothesized to be unrelated should not agree (discriminant validity). Correlation analysis and factor analysis are quantitative techniques used to assess whether variables are measuring the same underlying construct.

The reliability of a measure refers to its stability over time, that is, the consistency of answers given by the same individual to the same item. The reliability of survey items can be assessed using statistical methods, such as calculating mean absolute differences in scores on repeat measurement, coefficients of variation, kappa statistics, or correlation coefficients appropriate for the type of data (nominal, ordinal, or interval). Several types of reliability can be assessed. Test–retest reliability examines the correspondence between answers given by an individual when the item(s) is readministered over a brief interval (sufficiently brief so that an underlying change in health status is not anticipated to occur between administrations). Inter-rater reliability assesses how closely data obtained by different interviewers match. Cronbach’s alpha is commonly calculated as a measure of internal consistency, that is, how closely related a set of items are as a group.

The interpretability of the questionnaire refers to the ability to compare data from the survey to other available information. For example, responses of a patient population cannot be interpreted without some understanding of the responses of a healthy population. A related concept is the minimal clinically important difference (MCID), i.e., the minimal change in score considered to be clinically meaningful, as opposed to just statistically significant. As an example, Basra and colleagues published results of a longitudinal study among patients with inflammatory skin disorders. Patients (n = 107) were asked to complete the 10-item Dermatology Life Quality Index (DLQI) prior to starting a new treatment regimen. After 1–3 months of treatment, the questionnaires were administered a second time. Based on responses, patients were grouped into 4 categories: those having experienced “no change” (n = 23) showed a mean improvement of 2.7 points in the DLQI score, a “small change” (n = 31) showed a mean improvement of 3.3 points, a “moderate change” (n = 25) showed a mean improvement of 4.4 points, and a “large change” (n = 28) showed a mean improvement of 6 points. The authors recommended that 4 points be considered the MCID for the DLQI.

HRQoL Instruments Applicable to Older Adults

A number of HRQoL instruments have been developed to assess skin-related effects. Most of these instruments have been developed for the general population. However, since older adults were included in the development and validation process, many are applicable to older individuals. Table 2 shows a list of available instruments developed to measure HRQoL for skin-related conditions. Selected ones are discussed in greater detail below.

Instruments for General Well-being and Appearance

Farage Quality of Life Questionnaire

Despite the existence of numerous HRQoL measures, few if any are geared to evaluating the impact of consumer products on HRQoL. A general measure, the Farage Quality of Life Questionnaire (FQoL), was developed to assess the impact of products use on various aspects of HRQoL. The self-
Table 2  Examples of skin-related health-related quality of life measures for adults

<table>
<thead>
<tr>
<th>Disease(s)</th>
<th>Measure</th>
<th>Abbreviation</th>
<th>References</th>
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<tbody>
<tr>
<td><strong>General well-being and appearance</strong></td>
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<tr>
<td></td>
<td>Farage Quality of Life Questionnaire</td>
<td>FQoL</td>
<td>[38]</td>
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<tr>
<td></td>
<td>BeautyQoL Questionnaire</td>
<td>BeautyQoL</td>
<td>[41]</td>
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<tr>
<td><strong>Generic for dermatology</strong></td>
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<tr>
<td></td>
<td>Dermatology Life Quality Index</td>
<td>DLQI</td>
<td>[42, 79]</td>
</tr>
<tr>
<td></td>
<td>Dermatology Quality of Life Scales</td>
<td>DQoLS</td>
<td>[43, 79]</td>
</tr>
<tr>
<td></td>
<td>Family Dermatology Life Quality Index</td>
<td>FDLQI</td>
<td>[44, 79]</td>
</tr>
<tr>
<td></td>
<td>Skindex/Skindex-29/Skindex-16</td>
<td>Skindex</td>
<td>[45, 79, 80]</td>
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<tr>
<td></td>
<td>Impact of Chronic Skin Disease on Daily Life</td>
<td>ISDL</td>
<td>[49]</td>
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<tr>
<td><strong>Specific dermatologic conditions</strong></td>
<td></td>
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<tr>
<td>Acne</td>
<td>Acne Quality of Life Questionnaire</td>
<td>Acne-QoL</td>
<td>[79, 81]</td>
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<td></td>
<td>Acne Disability Index</td>
<td>ADI</td>
<td>[79, 82]</td>
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<tr>
<td>Alopecia</td>
<td>Kingsley Alopecia Profile</td>
<td>KPA</td>
<td>[79, 83]</td>
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<tr>
<td></td>
<td>Alopecia Areata Symptom Impact Scale</td>
<td>AASIS</td>
<td>[84]</td>
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<tr>
<td>Atopic dermatitis</td>
<td>Quality of Life Index for Atopic Dermatitis</td>
<td>QoLIAD</td>
<td>[79, 85]</td>
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<tr>
<td>Contact dermatitis</td>
<td>Dermatology-Specific Quality of Life for Contact Dermatitis</td>
<td>DSQL-CD</td>
<td>[50, 79]</td>
</tr>
<tr>
<td>Eczema</td>
<td>Dermatitis Family Impact Questionnaire</td>
<td>DFI</td>
<td>[42, 79]</td>
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<tr>
<td></td>
<td>Patient-Oriented Eczema Measure</td>
<td>POEM</td>
<td>[79, 86]</td>
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<td>Itch/pruritus</td>
<td>Itch Severity Scale</td>
<td>ISS</td>
<td>[52]</td>
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<td></td>
<td>Pruritus-specific</td>
<td>ItchyQoL</td>
<td>[54]</td>
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<td></td>
<td>Scalp dermatitis</td>
<td>Scalpdex</td>
<td>[55]</td>
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<td>Pruritus-related Life Quality Index</td>
<td>PLQI</td>
<td>[87]</td>
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<td>Leg ulcer</td>
<td>Charing Cross Venous Ulcer Questionnaire</td>
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<td>Leg and Foot Ulcer Questionnaire</td>
<td>LFUQ</td>
<td>[79, 88]</td>
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<td></td>
<td>Diabetic Foot Ulcer Scale</td>
<td>DFS</td>
<td>[58, 79]</td>
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<tr>
<td></td>
<td>Diabetic Foot Ulcer Scale – Short Form</td>
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<td>Pressure ulcer</td>
<td>Pressure Ulcer Quality of Life</td>
<td>PU-QOL</td>
<td>[61]</td>
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<td>Psoriasis</td>
<td>Psoriasis Disability Index</td>
<td>PDI</td>
<td>[76, 79]</td>
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<td></td>
<td>12-Item Psoriasis Quality of Life Questionnaire</td>
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<td></td>
<td>Psoriatic Arthritis Quality of Life Instrument</td>
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<td></td>
<td>REFlective evaLuation of psoriasis Efficacy of Treatment and Severity</td>
<td>REFLETS</td>
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<td></td>
<td>Psoriasis Area and Severity Index</td>
<td>PASI</td>
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<td>Onychomycosis</td>
<td>Onychomycosis Quality of Life Questionnaire</td>
<td>ONYCHO</td>
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<td>Rosacea</td>
<td>Rosacea-Specific Quality of Life</td>
<td>RosaqoL</td>
<td>[65]</td>
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<tr>
<td>Systemic lupus erythematosus</td>
<td>Lupus Patient-Reported Outcome tool</td>
<td>LupusPRO</td>
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<tr>
<td></td>
<td>Systemic Lupus Erythematosus Quality of Life Questionnaire</td>
<td>SLEQoL</td>
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<td></td>
<td>British Isles Lupus Assessment Group Index</td>
<td>BILAG Index</td>
<td>[79, 96]</td>
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<td></td>
<td>European Consensus Lupus Activity Measurement</td>
<td>ECLAM</td>
<td>[79, 97]</td>
</tr>
<tr>
<td></td>
<td>Systemic Lupus Erythematosus Disease Activity Index</td>
<td>SLEDAI</td>
<td>[79, 98]</td>
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<tr>
<td>Vitiligo</td>
<td>Vitiligo-specific quality-of-life instrument</td>
<td>VitiQoL</td>
<td>[99]</td>
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administered general FQoL consists of 27 general items scored on a Likert scale and covering overall QoL (1 item), well-being (12 items), and energy and vitality (14 items). The Well-Being domain has 3 subscales: Emotion, Self-Image, and Self-Competence. The Energy and Vitality domains also have 3 subscales: Personal Pleasure, Physical State, and Routine Activity. A recent publication described the translation of the FQoL into Chinese [39].

**BeautyQoL Questionnaire**

An improvement in facial attractiveness is associated with positive changes in self-esteem and in the emotional and social dimensions of one’s life [40]. The BeautyQoL questionnaire was developed specifically to assess QoL relevant to cosmetic products and physical appearance [41]. This instrument was developed in 13 countries representing 16 different languages. Development of the BeautyQoL questionnaire followed a 3-phase validation process. Initial items were generated via face-to-face interviews of 309 subjects in 10 different countries. The second phase was an acceptability study performed on 874 subjects from 13 countries. In the final phase, 3231 subjects were recruited in those countries to complete the questionnaire. A retest was performed 8 days later on a subgroup of 652 subjects. The resulting questionnaire consists of 42 items in 5 dimensions: social life, self-confidence, mood, energy, and attractiveness. The measure has been translated into 16 languages.

**Instruments Suitable for Dermatologic Conditions in General**

**The Dermatology Life Quality Index (DLQI)**

The DLQI is a simple, 10-question, validated questionnaire used widely in clinical settings and available in more than 40 languages [42]. The DLQI was developed based on the responses of 120 patients with various skin diseases who were asked how their disease and its treatment affected their life. For further validation, the DLQI was subsequently administered to 200 consecutive patients attending a dermatology clinic. Analysis of the responses revealed that atopic eczema, psoriasis, and generalized pruritus have a greater impact on HRQoL than do acne, basal cell carcinoma, and viral warts. When the instrument was administered to 100 healthy volunteers (i.e., no apparent dermatologic disease), mean scores were very low (better), supporting the validity of the instrument. A 1-week, test–retest reliability analysis in 53 patients found that the DLQI instrument was highly reliable [42].

**Dermatology Quality of Life Scales**

The Dermatology Quality of Life Scales (DQoLS) was developed to assess the impact of skin conditions on patients’ psychosocial state and everyday activities [43]. The instrument was developed using written input from 50 dermatology outpatients who were asked about all the ways in which their skin condition affected them. Responses were distilled into a list of 17 psychosocial items, 12 physical activity items, and 12 symptom items. The resulting questionnaire was completed by 118 patients, and responses were used to evaluate internal consistency, test–retest reliability, and construct validity. Factor analysis grouped the psychosocial and physical activity items into four subscales each. The 12 questions on symptoms did not cluster and were, therefore, treated as an overall symptom score. The DQoLS can be completed quickly by patients to provide measures of patient-perceived impacts to complement traditional clinical indicators.

**The Family Dermatology Life Quality Index**

The Family Dermatology Life Quality Index (FDLQI) is a 10-item questionnaire administered to patients’ family members to measure the indirect impact of skin disease on the family [44]. The FDLQI is responsive to changes in the patient: family members’ scores changed in association with improvement.
or worsening of the patient’s condition. There were strong statistical associations between FDLQI scores and the patients’ DLQI scores, FDLQI scores and inflammatory versus noninflammatory disease, and FDLQI scores and the severity of the patient’s disease. There was a positive relationship between FDLQI scores of the family members and the patient’s disease severity, as measured by the DLQI. Thus, the FDLQI has been shown to be a simple and practical additional outcome measure in clinical practice and evaluation research.

Skindex
The Skindex instrument is widely used to evaluate dermatological HRQoL. The original 61-item, self-administered Skindex questionnaire was first developed in the mid-1990s [45] and focused on skin diseases and the frequency and severity of their impact on QoL: cognitive effects, social effects, depression, fear, embarrassment, anger, physical discomfort, and physical limitations. Several revised versions of the instrument have been developed to improve upon discriminative and evaluative capability and administration time. The 29-item Skindex-29 [46], which takes about 5 min to complete, has since been translated into eleven languages. The even shorter, single-page 16-item Skindex-16 (Table 3) [47] has been translated into 16 languages. At the time of writing this chapter, a Chinese translation is being validated [48].

The Impact of Chronic Skin Disease on Daily Life
The Impact of Chronic Skin Disease on Daily Life (ISDL) instrument assesses the effect of chronic skin diseases and their treatments on both dermatology-specific and generic aspects of HRQoL [49]. Specifically, the ISDL assesses physical functioning, itching/scratching, pain, fatigue, stigmatization, psychological functioning, illness cognitions, and social support. The reliability and validity of the instrument were assessed in patients with psoriasis or atopic dermatitis. The authors demonstrated reliability and high test–retest reliability. In addition, the ISDL was sensitive to changes in health status resulting from ultraviolet B radiation therapy or cognitive behavioral therapy for itching [49].

Measures Suitable for Specific Dermatologic Conditions

Contact Dermatitis

Dermatology-Specific Quality of Life Instrument for Contact Dermatitis
The Dermatology-Specific Quality of Life Instrument for Contact Dermatitis (DSQL-CD) was created to quantify the effect of skin disease on physical discomfort and symptoms, psychological well-being, social functioning, self-care activities, performance at work or school, and self-perceptions [50]. Reliability and validity were assessed in patients with contact dermatitis or acne vulgaris. The validity of the instrument was assessed by correlating DSQL scores with global ratings of bothersome symptoms and their perceived severity and by the instrument’s ability to discriminate among clinically defined severity-of-illness groups. Test–retest reliability was assessed at 3 and 7 days. The instrument’s domains had good internal consistency and test–retest reliability. The subscale scores were also moderately to highly correlated with globally validated ratings of symptoms of distress and with overall disease severity. As expected, patients with severe contact dermatitis or scarring from acne vulgaris had worse DSQL scores than those with milder disease.
Chronic pruritus is a common condition among older adults. The most common cause of chronic pruritus or itch is dry skin, which is a natural consequence of skin aging [22]. In addition, a number of medications commonly taken by older individuals can induce pruritus, such as antihypertensive drugs, anticoagulants, and lipid-lowering drugs [51]. A number of instruments have been developed to evaluate the impact of pruritus.

**Itch Severity Scale**

The *Itch Severity Scale* (ISS) is a self-administered questionnaire to measure the severity of pruritus [52]. To develop the instrument, an existing pruritus instrument was modified and administered to patients with psoriasis-associated pruritus, along with the RAND-36 Health Status Inventory [53] (a generic health status measure), and the DLQI. The resulting ISS instrument contains just seven questions and was demonstrated to be a valid and reliable means of assessing the severity of pruritus as well as the effectiveness of treatments [52].
ItchyQoL

ItchyQoL is another pruritus-specific HRQoL instrument [54]. It includes 22 pruritus-specific questions covering three major domains: symptoms, functional limitations, and emotions. Initially, two versions of the instrument were created based on patient interviews and items from Skindex-16 and Skindex-29, one with “frequency” questions and the other with “bother” questions. Eighty-nine patients took part in the validation phase and 101 patients participated in the clinical application phase. The final instrument contains 27 questions: 18 capture both frequency and bother and the remaining nine items pertaining to emotion assess frequency only. Although the authors cited lack of generalizability and potential selection bias as possible limitations, they found this initial pruritus-specific questionnaire to be reliable, valid, and responsive [54].

Scalpdex

Scalpdex [55] is the first HRQoL instrument specific for scalp dermatitis. Scalpdex is based on three major domains of quality of life: symptoms, functioning, and emotions. The 23-question instrument was demonstrated to be reliable, valid, and responsive. Scalpdex can be used by clinicians to determine which aspect of the disease bothers the patient the most so as to choose treatment options for maximum benefit [55].

Leg and Foot Ulcers

Charing Cross Venous Ulcer Questionnaire

The Charing Cross Venous Ulcer Questionnaire (CCVUQ) [56] is a 21-item self-administered instrument to assess patients’ perceptions of their health when venous ulceration is present. Items for the questionnaire were selected from patient interviews and a literature review. The resulting questionnaire was administered to 98 patients with venous ulcers. Concurrently, patients were asked to complete an established HRQoL instrument (the 36-Item Short Form Health Survey (SF-36) [57]) for comparison. The CCVUQ instrument showed good reliability and internal consistency and good test–retest reliability. Results correlated well with the SF-36.

Diabetic Foot Ulcer Scale

The Diabetic Foot Ulcer Scale (DFS) [58] is a 64-item self-administered instrument developed to assess the impact of diabetic foot ulcers and their treatment on patients’ QoL in a broad range of areas, including physical health, leisure and daily activities, attitudes and emotions, and social interactions. Items for inclusion were based on interviews and focus group discussions with patients. The resulting instrument was initially tested on 173 patients with diabetes: 48 with current foot ulcers, 54 with healed foot ulcers, and 71 with no history of foot ulcers. The results demonstrated good internal consistency and adequate test–retest reliability. In addition, the instrument was responsive to changes in wound status over time. A shorter instrument, the Diabetic Foot Ulcer Scale – Short Form (DFS-SF) [59] was developed in conjunction with clinical trials of treatments for leg ulcers. This 29-item self-administered questionnaire showed good internal consistency, reliability, and construct validity and demonstrated responsiveness to ulcer healing.

Pressure Ulcers

Pressure (decubitus) ulcers are localized areas of tissue necrosis involving the skin and underlying tissue, usually over a bony prominence [60]. The sacrum, buttocks, and heels are particularly vulnerable [61]. Pressure ulcers are common in elderly patients with limited mobility. As reviewed by Farage and coauthors [60], the prevalence of pressure ulcers among patients has been reported to be 25% in skilled
nursing home facilities, 14% in acute care facilities, and 12% in home care. People aged 70–75 have double the risk of pressure ulcers compared with those aged 55–69 years. Many affected patients have a variety of concomitant health and function problems.

**Pressure Ulcer Quality of Life**

A *Pressure Ulcer Quality of Life* (PU-QoL) measure is being developed to evaluate the impact on HRQoL of the pressure ulcers and of interventions for preventing and treating them [61]. The most recent PU-QoL version consists of 13 scales (87 items): pain, exudate, odor, sleep, vitality, mobility, daily activities, mood, anxiety, self-consciousness and appearance, autonomy, isolation, and participation [62]. It can be self-administered or administered with the assistance of an interviewer. At the time of writing of this chapter, further development work is still needed on the PU-QoL to ensure that questions and approaches to administration meet the needs of the broad range of individuals with pressure ulcers. Nevertheless, this is a promising approach to developing of a patient-reported outcome measure for pressure ulcers.

**Rosacea**

Rosacea is a chronic dermatologic condition that increases in prevalence with age. In men, the prevalence of rosacea increases abruptly after age 50 and reaches a peak of 3.9% in the 76- to 80-year age group [63]. In women, the increase in prevalence occurs earlier, i.e., after 35 years of age, and peaks at 2.8% in the 61- to 65-year age group [63]. Its clinical appearance varies, but rosacea most recognizably manifests as erythema on the central area of the face or as phymatoid changes around the nose. Pharmacological treatments are often inadequate [64]; thus, a rosacea-specific instrument could be beneficial in assessing the patient’s perspective on treatment effectiveness.

**Rosacea-Specific Quality of Life Instrument**

Based on in-depth patient interviews [65], three domains pertinent to HRQoL were identified: symptoms, functioning, and emotions. To validate the instrument, patients with rosacea were randomly selected from dermatology clinics, and the Skindex-29 questionnaire, 21 rosacea-specific questions, and five questions about general health were administered by telephone. Because rosacea severity can vary throughout the year, the interviews were performed over a 4-year period. The patients answered all questions at baseline, at 72 h (allowable range: 3–7 days), and at 4–6 months. Follow-up interviews allowed inconsequential or insensitive questions to be eliminated. The process yielded the 21-item *Rosacea-Specific Quality of Life* (RosaQoL) instrument [65] (Table 4). The RosaQoL’s reliability, validity, and responsiveness were assessed by psychometric and statistical analyses. The developers believe it to be a promising, practical instrument for use in both clinical and research settings [65].

**Utility/Value/Preference Measures for Dermatologic Conditions**

Utility measures can provide important information for assessing cost-effectiveness of treatment approaches and the desirability for certain health outcomes. Instruments have been developed to evaluate WTP for control or cure of a medical condition and/or willingness to live a shorter life without the current medical condition (time trade-off) [66]. Perceived utility or value varies not only from condition to condition but also from patient to patient with a given condition, by assessment method, and by respondent type [13, 67–70]. For example, utility measures for controlled atopic eczema, uncontrolled atopic eczema, controlled psoriasis, and uncontrolled psoriasis have been evaluated in a 2006 study in the general population in Germany and in German patients with atopic eczema or psoriasis [67]. On the time trade-off, the median score for controlled atopic eczema was 0.97, indicating that respondents were willing to give up a median of 3% of their life expectancy (＝[1.0 − 0.97] × 100%) in order to have perfect health (no atopic eczema). For controlled psoriasis, the median utility was 0.93. By contrast,
median utilities were much lower for uncontrolled atopic eczema (0.64) and uncontrolled psoriasis (0.56).

The study also asked people about WTP. People from the general population would be willing to pay a median of €50/month for an effective treatment (with no side effects) for controlled atopic eczema, €150/month for uncontrolled atopic eczema, €75/month for a treatment for controlled psoriasis, and €200/month for uncontrolled psoriasis. Another study reported that patients with psoriasis would be willing to pay on average 14% of their monthly income to get rid of their psoriasis [71].

Seidler and colleagues evaluated WTP among dermatology patients diagnosed with a variety of skin diseases [72]. These investigators reported patients were willing to pay a median of 2% of their annual income for a cure of their condition or 1.6% for control of their condition. A group of investigators in Germany conducted studies of utility measures for several dermatologic conditions. In a study of 1,023 patients with vitiligo [73], they reported that 32.9% of patients would pay a median of €3,000 in order to achieve complete disease remission. In a 2013 study among patients with rosacea (n = 475), subjects were willing to pay a median of €500 for complete healing [74]. Finally, in a study of patients with atopic dermatitis (n = 384), the median WTP for complete healing was €1,000 [75].

Several researchers have modified the time trade-off method by asking patients how many hours each day they would be willing to devote to treating their skin condition if the treatment was curative [71, 76, 77]. Patients with psoriasis would be willing to spend a mean (SD) of 2.8 (3.7) hours each day to be relieved of their psoriasis [71], whereas patients with port wine stains would be willing to devote 1.2 (0.9) hours each day to be rid of their port wine stains [77].

In a particularly comprehensive study of utility measures for dermatologic conditions, life expectancy time trade-off utilities for 20 different skin conditions were evaluated in 236 patients [78]. The mean

<table>
<thead>
<tr>
<th>Rosacea-QoL item</th>
<th>Hypothesized construct</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I worry that my rosacea may be serious</td>
<td>Emotion</td>
</tr>
<tr>
<td>2. My rosacea burns or stings</td>
<td>Symptom</td>
</tr>
<tr>
<td>3. I worry about scars from my rosacea</td>
<td>Emotion</td>
</tr>
<tr>
<td>4. I worry that my rosacea may get worse</td>
<td>Emotion</td>
</tr>
<tr>
<td>5. I worry about side effects from rosacea medications</td>
<td>Emotion</td>
</tr>
<tr>
<td>6. My rosacea is irritated</td>
<td>Symptom</td>
</tr>
<tr>
<td>7. I am embarrassed by my rosacea</td>
<td>Emotion</td>
</tr>
<tr>
<td>8. I am frustrated by my rosacea</td>
<td>Emotion</td>
</tr>
<tr>
<td>9. My rosacea makes my skin sensitive</td>
<td>Symptom</td>
</tr>
<tr>
<td>10. I am annoyed by my rosacea</td>
<td>Emotion</td>
</tr>
<tr>
<td>11. I am bothered by the appearance of my skin (redness, blotchiness)</td>
<td>Emotion</td>
</tr>
<tr>
<td>12. My rosacea makes me feel self-conscious</td>
<td>Emotion</td>
</tr>
<tr>
<td>13. I try to cover up my rosacea (with makeup)</td>
<td>Functioning</td>
</tr>
<tr>
<td>14. I am bothered by the persistence/recurrence of my rosacea</td>
<td>Emotion</td>
</tr>
<tr>
<td>15. I avoid certain foods or drinks because of my rosacea</td>
<td>Functioning</td>
</tr>
<tr>
<td>16. My skin feels bumpy (uneven, not smooth, irregular)</td>
<td>Symptom</td>
</tr>
<tr>
<td>17. My skin flushes</td>
<td>Symptom</td>
</tr>
<tr>
<td>18. My skin gets irritated easily (cosmetics, aftershaves, cleansers)</td>
<td>Symptom</td>
</tr>
<tr>
<td>19. My eyes bother me (feel dry or gritty)</td>
<td>Symptom</td>
</tr>
<tr>
<td>20. I think about my rosacea</td>
<td>Emotion</td>
</tr>
<tr>
<td>21. I avoid certain environments (heat, humidity, cold) because of my rosacea</td>
<td>Functioning</td>
</tr>
</tbody>
</table>

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(SD) utility for all skin conditions was 0.943 (0.124), but varied depending on the disorder in question. For example, pruritus and related conditions had a utility of 0.915 (0.145), and ulcers had a utility of 0.923 (0.154).

**Conclusion**

Older adults experience a number of skin diseases and disorders that adversely affect quality of life. In the past several years, a number of disease-specific HRQoL measures have been developed for the general dermatology patient to assess the effects of treatment and disease progression, perceptions of well-being, and the value that patients place on their dermatologic state of health. Some instruments have been validated and further refined over time, while others are in earlier stages of development. Opportunity exists for developing and validating HRQoL specifically for dermatologic conditions most pertinent to older patients. Dermatology-specific HRQoL instruments will continue to be investigated with the common goal of increasing understanding of how skin diseases and their treatment affect HRQoL in people of all ages.

**Cross-References**

- Aging Skin: Some Psychosomatic Aspects
- Psychological and Social Implications of Aging Skin: Normal Aging and the Effects of Cutaneous Disease

**References**


