

Chapter 2

The Impact of Skin and Hair Disease in Ethnic Skin

Temitayo Ogunleye and Susan C. Taylor

The ethnic/racial demographic of the United States is in the midst of significant change and physicians must be adept at recognizing and effectively treating dermatologic disease states in patients with skin of color. Inherent in effectively treating these cutaneous diseases is sufficiently understanding the patient's viewpoint about his/her disease, as well as hindrances to treatment, compliance, patient satisfaction, and access to leading treatment modalities. Information about the physical and psychosocial impact of a disease can be used to guide treatment practices and appropriately address patient expectations. Additionally, the recognition of psychosocial and physical burdens associated with cutaneous diseases (i.e., health-related quality of life) will become paramount to support treatment appeals as reimbursement for treatment of various conditions is becoming more limited, while some diseases are deemed purely cosmetic and coverage for treatment is denied.

Health-Related Quality of Life

Health-related quality of life (HRQL, HRQoL) instruments assess disease burden using physical, social, and psychological measures [1, 2]. These broadly encompassing measures are important in dermatologic diseases in particular, as health status or physical impairment may not fully correlate with the impact of the disease on the patient's life, nor correlate with severity of disease [3, 4]. Several

S.C. Taylor (✉)

Department of Dermatology, Hospital of the University of Pennsylvania, Penn Medicine, Washington Square, 16th Floor, 800 Walnut Street, Philadelphia, PA 19107, USA
e-mail: drstaylor1@aol.com

T. Ogunleye

3737 Market St. 11th Floor, Philadelphia, PA 19104, USA

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dermatology-specific quality of life (QOL) questionnaires have been developed, including the Short Health Form 36 (SF-36) [5], the Skindex-29 [6] and the Dermatology Life Quality Index (DLQI) [7] that assess disease burden in general dermatologic disease (Table 2.1). Recently, disease-specific QOL questionnaires have been developed such as the Cardiff Acne Disability Index [8], Psoriasis Disability Index [1], Quality of Life Index for Atopic Dermatitis [9], Chronic Urticaria Quality of Life Questionnaire [10], and Melasma Quality of Life scale (MELASQOL) [3].

The DLQI, developed in 1994, was the first dermatology-specific QOL instrument [7] (Table 2.1). It is a widely used 10-question validated questionnaire that has been used in over 40 different skin conditions in over 80 countries. The SF-36 questionnaire consists of 36 items forming 8 domains (Table 2.1) [11]. Several versions of this questionnaire with fewer questions also exist. The Skindex-29 consists of 29 items forming 3 scales: symptoms, emotions, and functioning [6, 12] (Table 2.1). Higher scores in the DLQI and Skindex 29 correlate with decreased quality of life, while higher scores in the Skindex-29 instrument correlate with increased quality of life. Clinical meaning of scores is usually determined via a statistically significant difference of scoring after some intervention or comparison of mean scores to other diseases or the general population, although some have created banding of scores to assign clinical meaning to absolute scores [13] (Table 2.2). Issues with the banding scoring method include wide variability of bands created in various studies, and possible lack of generalizability based on population or disease states studied [13].

Table 2.1 Dermatology specific quality of life questionnaires

Name of survey instrument	DLQI	SF-36	Skindex 29
Areas examined	Symptoms Feelings Daily activities Leisure Work/school Personal relationships Treatment	Physical functioning Social functioning Role physical (limitations in usual activities because of physical problems) Role emotional (limitations in usual activities because of emotional problems) Bodily pain Mental health Vitality General health perception	Symptoms (e.g., itch, pain, and irritation) Emotions (e.g., worry, shame, embarrassment, frustration, and depression) Functioning (e.g., sleep, social life, social isolation, sexuality, work, and hobbies)
Number of questions	10	36	29
Scoring	0–30	0–100	0–100

Table 2.2 Sample of proposed scoring interpretation

DLQI (Hongbo) [13, 65]	Skindex 29 (Chen) [13]	QoL effect
0–1	0–10	None/very little
2–5	11–25	Mild
6–10	26–50	Moderate
11–20	51–70	Severe
21–30	71–100	Very severe

In this chapter, we examine QOL studies that target conditions specific to or more common in skin of color patients and in particular those improperly deemed as aesthetic in nature. Providing a better understanding of the extent of disease burden will result in improved care of these patients.

Disorders of Pigmentation

Disorders of pigmentation occur commonly in individuals with skin of color and practice surveys reveal that they are the third most common presenting complaint in darker skinned individuals [14]. Although some physicians and insurance companies may consider these issues cosmetic, pigmentary disorders can be very distressing to the affected individual and can have long-lasting psychosocial implications. Disorders of hypopigmentation, specifically vitiligo, and of hyperpigmentation, including melasma and postinflammatory hyperpigmentation, have been examined to understand the associated psychosocial and physical burdens on patients.

Vitiligo

Vitiligo is an autoimmune disorder involving melanocytes, leading to loss of pigmentation in areas of skin and mucous membranes (Fig. 2.1). Depigmented or hypopigmented well-demarcated patches are seen most frequently on the hands, forearms, feet and face, but may be found anywhere. Involvement varies and may be localized, generalized or universal. In individuals with skin of color, the contrast between the normal darkly pigmented skin and the depigmented or white vitiliginous skin makes it a highly visible disorder.

The lesions of vitiligo are asymptomatic, contributing to the labeling of the disease as a cosmetic concern in some Western countries, which subsequently has led to undertreatment and decreased insurance coverage for treatments [15–17]. However, altered skin color as well skin color that is not uniform can negatively affect the perception of general health, wealth, worth, and desirability of an



Fig. 2.1 Vitiligo on the back of an affected individual. Note the large patches of depigmentation, with scattered small confetti macules

individual [18]. Vitiligo can lead to social exclusion and is a major medical problem in India [19, 20]. In that society, vitiligo has been mistaken for infectious diseases such as leprosy, leading to shunning [19]. Additionally, it can affect marriageability and render a young woman unable to get married [21, 22]. Hence, the burden of illness for vitiligo can have far-reaching implications beyond the cosmetic appearance.

Gender differences in quality of life have been demonstrated in women with vitiligo where there is evidence of increased depression, anxiety, and community isolation [23]. In a 2016 review of 21 studies assessing the DLQI score of 4721 patients with vitiligo, ten of these studies revealed impaired quality of life for both genders, but female patients had more QoL impairment (total mean 8.03) than males (5.99) [23].

A Netherlands study of 245 patients using the Skindex 29 and SF-36 found that adult patients with generalized vitiligo had a low mental HRQL [11], comparable with that of patients with symptomatic skin diseases such as eczema [24, 25], psoriasis [24, 26, 27], and hand eczema [28]. Patients with dark skin (skin type IV–VI) and those who had treatment in the past had significantly more impairment in psychosocial functioning ($P < 0.01$) [11]. This difference may be attributable to the ease of visibility of vitiligo in darker skinned patients. Authors also propose that patients who have been treated in the past may have less hope regarding future treatment of their disorder, and have overall less acceptance of their disease [11]. A 2015 cross-sectional study of 300 patients also found that darker skinned patients felt ‘(their) vitiligo ha(d) repercussions on (their) physical appearance’ ($P = 0.042$) and ‘managing (their) vitiligo on a daily basis (wa)s a burden’ ($P = 0.037$) [29]. Fair skinned individuals were more concerned about skin cancer risks from vitiligo ($P = 0.039$) [29].

Overall, these studies suggest that regardless of skin type, patients with vitiligo experience significant disease-related burden and self-perceived stress [11, 29]. However, patients with darker skin may have increased emotional burden in comparison with their lighter skinned counterparts [29]. In addition, treatment of vitiligo was also found to be an independent stressor that interfered negatively with quality of life [11]. Lastly, fair-skinned vitiligo patients had increased concern about skin cancer development, highlighting an opportunity for education as recent research indicates that patients with vitiligo have a decreased risk of melanoma and nonmelanoma skin cancer [29–31].

Melasma

Melasma is a relatively common disorder of acquired hyperpigmentation characterized by symmetric, poorly demarcated brown macules and patches that occur primarily on sun-exposed areas on the face and neck (Fig. 2.2). The three clinical patterns of melasma are centrofacial (most common), malar, and mandibular. Risk factors include exposure to ultraviolet radiation, genetics, hormonal therapy and pregnancy, phototoxic drugs, and anticonvulsant medications [32].



Fig. 2.2 Melasma on the forehead of an affected individual with poorly demarcated *dark brown macules* coalescing into patches

Melasma affects all races but is especially prevalent in those with darker skin types (Fitzpatrick skin types III–VI) and has been frequently reported in patients of Hispanic, African American, Arab, South Asian, Southeast Asian, and East Asian descent [32]. Additionally, melasma is more prevalent in women, with men comprising only 10% of all cases [33].

In 2003, Balkrishnan et al. developed a new health-related quality of life (HRQL) instrument for women with melasma by merging Skindex-16 and other skin pigmentation questionnaires [3]. This questionnaire differed from previous dermatological HRQL instruments such as the DLQI and Skindex-16, which placed equal weight on physical and psychological effects of skin disease [6, 7]. However, since the physical discomfort from melasma is negligible, but psychosocial effects may be severe, a more targeted questionnaire was necessary to adequately measure the burden of this disease. MELASQoL was developed from questions more relevant to melasma-specific QoL issues and with greater emphasis on the emotional and psychosocial aspects [3].

The MELASQoL by Balkrishnan et al. [3] identified social life, leisure and recreation, and emotional well-being as being most affected by melasma, whereas, a 2006 validation study of the MELASQoL in Latino patients, reported the QoL domains most affected by melasma were emotional well-being, social life, physical health, and finances [4]. In Asian patients in a 2016 Singapore study of 49 women, the strongest predictors of decreased HRQoL in women with melasma were increased disease severity ($P < 0.05$), increased fear of negative evaluation ($P < 0.01$), and the belief that their HRQoL would be better if they did not have melasma ($P < 0.01$) [34].

In summary, the MELASQoL questionnaire has been helpful in more accurately elucidating the psychosocial burden of melasma. Patients report difficulties in interpersonal relationships, ability to enjoy leisure and recreational activities, and a financial burden, likely from failed attempts from treatment [3, 35, 36]. These studies reinforce the need for more successful treatments of this condition that can have impact that reaches beyond cosmetic disfigurement. This tool has been successfully adapted and validated in multiple languages including Spanish, Brazilian Portuguese, Hindi and French. Since melasma is common worldwide, particularly in individuals with skin of color, translation to other languages will be helpful in understanding the impact of melasma in difference countries and to increase the body of HrQoL data for this condition.

Acne and Postinflammatory Hyperpigmentation

Acne is one of the most frequently encountered diseases in dermatology for individuals 15–40 years of age in the United States [37] Acne is also the most common dermatological diagnosis in non-Caucasian patients [38–41]. In a community-based

photographic study, clinical acne was found to occur most commonly in Black/African American (37%), Hispanic/Latina (32%), and Asian (30%) women, more so than in Continental Indian (23%) and White/Caucasian (24%) women [42].

Clinically, acne may present with open and closed comedones and/or a mixture of inflammatory papules, pustules, and nodules most commonly on the face, chest, and back of varying severity. In particular, postinflammatory hyperpigmentation (PIH) is a prominent sequelae of acne in darker skin tone, and can be a source of increased quality of life burden in skin of color patients. Acne is likely the most common cause of PIH in patients with skin of color, especially in Black patients where up to two-thirds of patients may experience PIH [42, 43]. If the inciting inflammatory condition improves or resolves but postinflammatory hyperpigmentation remains unaddressed, the patient will often consider the treatment to be a failure [44].

Callender et al. surveyed a diverse sampling of 208 women and found that 70% non-White/Caucasian women surveyed felt that their skin type required targeted attention and two-thirds (66.3%) desired an acne treatment that was designed to meet the needs of their skin [43]. More than 75% preferred to visit a healthcare professional who had experience treating acne in non-White/Caucasian women [43]. In addition, the majority of the women surveyed (85.1%) would be interested in an acne treatment that had been proven effective in treating acne for their race, ethnicity, or skin type [43]. The types of information considered most convincing in proving the efficacy of an acne treatment were scientific data or statistics (33.7%), recommendation by a dermatologist (17.8%) or friend/family member (15.8%), photographs (13.9%), primary care physician recommendation (10.9%), and other types of information (8.0%) [43].

Acne was shown to be burdensome and associated with low QoL, negative self-perceptions and symptoms of depression/anxiety in the Callender study [43]. Levels of social and emotional problems in acne patients were similar to that of psoriasis patients [45], and even those with severe chronic disabling diseases, such as arthritis and diabetes [46].

Acne in skin of color patients has the potential sequelae of postinflammatory hyperpigmentation that can add to the burden of disease. Clearing PIH was most important for many of the non-White/Caucasian women studied by Callender (41.6%; $p < 0.0001$) but was a lesser concern for White/Caucasian women (8.4%) [43]. Surveys also suggest that this patient population views a dearth of appropriate treatments and understanding of acne in their skin type, indicating a potential need for better products made for darker skin types [43]. Improved education of dermatologists regarding their approach in darker skin types including aggressive treatment of inflammatory lesions to decrease PIH and concomitant treatment of PIH may improve both clinical and QoL outcomes.

Keloids

Keloids represent an exaggerated healing response to trauma, resulting in irregular deposition of collagen beyond the boundaries of the original injury. Erythematous to hyperpigmented firm or rubbery nodules/plaques are seen, extending beyond the original trauma, and sometimes with no known antecedent trauma. Although sometimes considered a cosmetic issue, keloids are often painful, itchy, and cause a burning sensation. Keloid scarring is more prevalent in those of African, Asian, and Hispanic descent [47]. Most studies regarding keloids focus on the efficacy of available treatment options, but keloids have a significant effect on the quality of life.

A 2015 study of 108 keloid patients revealed that keloid disease had a large impact on the emotional well-being of patients [48]. Nearly half of the patients (48%) had severe emotional symptoms and about a quarter reported severe problems on the symptomatic and functional scale of the Skindex-29 questionnaire, such as itching and pain [48]. HRQL reduction was similar to the burden of diseases such as psoriasis, dermatitis, arthritis, and cancer [49]. Importantly, itching and pain were associated with the largest HRQL impairment, while cosmetic factors such as color, thickness, pliability, and irregularity of the scar were less related [48].

Another study of 130 patients with scars stratified based on type found that physiological and hypertrophic scars had little impact on the quality of life, while keloidal scars and atrophic scars more strongly decreased quality of life not only related to symptoms but also due to influences on daily activities, leisure and personal relationships [50].

Keloid scars can be disfiguring, but are a significant source of physical and psychosocial impairment. Importantly, QoL studies suggest that physical impairment is more burdensome than cosmetic appearance, highlighting the non-cosmetic and necessary nature of treatment [49, 50].

Alopecia

Hair loss is a common complaint in skin of color patients and several studies have shown that patients with alopecia have psychological sequelae [51–53]. Since alopecia is largely considered to be an aesthetic condition, ill feelings can be exacerbated by health care providers who may underestimate the impact of hair loss on such patients.

Alopecia can be categorized into scarring or non-scarring subtypes based on the clinical finding of loss of follicular ostia in areas of involvement, and the pathologic presence of decreased number of viable follicles and follicular scarring. Alopecia areata, androgenetic alopecia, telogen effluvium and early traction alopecia are the main types of non-scarring alopecia, while lichen planopilaris, central centrifugal cicatricial alopecia, dissecting cellulitis, acne keloidalis nuchae and late stage traction alopecia are the main types of scarring alopecia. Certain types of scarring

hair loss such as traction alopecia or central centrifugal scarring alopecia occur with increased frequency in darker skinned populations, particularly women. However, quality of life studies specific to these conditions are few.

A study of 50 South African women with alopecia found on a scale ranging from 0 (high QoL) to 100 (severely decreased QoL) a mean QLI of 67, indicating notable disease burden [54]. The factors with the highest impact were those relating to self-image (56.3%) and relationships and interaction with other people (34.8%) [54]. Specifically, subjects expressed concern that their children may develop alopecia or that their own condition would worsen, not being able to forget about the presence their alopecia, and worries about cost. The presence of symptoms such as itching were of less importance (8.9%) [54].

Another study examining 105 British men and women with primary cicatricial alopecia found that 19% of patients demonstrated a severe impact (DLQI score ≥ 11) on their QoL [55]. Interestingly, increasing age, being female and having $<25\%$ of hair loss were associated with better illness perceptions, less psychological distress, and higher QoL [55]. Based on these results, practitioners may consider more thorough evaluation for psychosocial issues in male patients with primary cicatricial alopecia who may have higher disease burden than some practitioners would anticipate.

Similar impact on quality of life was seen in patients with non-scarring hair loss including alopecia areata, androgenic alopecia, and telogen effluvium [56]. A 2012 study of 104 subjects with these conditions using the Skindex-16 instrument found a mean score of 57.3 (SD ± 16.2), indicative of moderately decreased quality of life [56]. The emotions domain reflected the lowest QoL (mean = 83.8 ± 15.2), followed by function domain (mean = 50.2 ± 30.0) and symptoms domain (mean = 19.9 ± 19.9), again suggesting that the emotional burden can be more influential to the well-being of the patient than the physical burden of these conditions [56].

In general, these studies confirm the emotional impact of hair loss in patients in a quantitative fashion. As the primary caretakers of these conditions in medicine, dermatologists should continue to treat both the hair disease process, as well as the psychosocial distress of the patients. By addressing both, we may be able to alleviate unnecessary fears of patients, increase patient satisfaction, and improve patients' overall quality of life.

Sarcoidosis

Sarcoidosis is a granulomatous disease that may involve any organ. The disease course is highly variable, ranging from an asymptomatic state to a progressive condition that may, occasionally, be life-threatening. The pathologic hallmark of sarcoidosis is the granuloma that may resolve spontaneously or with anti-sarcoidosis therapy. The typical cutaneous findings are reddish brown papules and plaques found anywhere on the body, including the face, but are highly variable

and include subcutaneous, ulcerative, lichenoid, psoriasiform, verrucous, and hypopigmented forms.

Sarcoidosis affects all races, but African-American women have the highest rates of sarcoidosis in the United States, including the highest rates of chronic cutaneous sarcoidosis [57]. Particularly in cutaneous cases with quiescent lung disease, sarcoidosis may be treated less aggressively secondary to the nonlife-threatening nature of cutaneous disease [58]. However, an important alternative indication for treatment includes decreased quality of life.

Previous studies have shown that sarcoidosis experts are relatively poor judges of the impact of the disease on the patient's quality of life [59], and initiate treatment based on increases in serum angiotensin-converting enzyme levels or nodularity on chest imaging, which may not translate into appreciable impact on patient quality of life [58]. However, studies examining HRQL as a primary outcome in sarcoidosis studies are scarce. The Sarcoidosis Health Questionnaire (SHQ) is a 29-item validated sarcoidosis-specific survey assessing the impact of sarcoidosis involvement of multiple organ systems, but only has one question relating to the skin, and therefore may not adequately capture cutaneous burden on quality of life [60]. The Sarcoidosis Assessment Tool (SAT) is a new quality of life instrument developed specifically for sarcoidosis that includes cutaneous disease in addition to pulmonary and ophthalmic involvement [61–63]. Skin Concerns and Skin Stigma scores of the SAT range from 0 to 40 and 0 to 20, respectively, with higher scores correlating with greater burden [63].

In a small cross-sectional study of 13 patients designed to examine the validity and reliability of other cutaneous sarcoidosis outcome instruments, the Skindex-29, DLQI, and the SAT were given [64]. The mean Skindex-29 Emotions, Symptoms, and Functioning domain scores were 65.8, 44.6, and 42.9, respectively, indicating that patients were severely impacted emotionally by their disease, and their symptoms of itch/pain at least moderately affected their lives. The mean SAT Skin Concerns and Skin Stigma raw sum scores were 13.3 and 11.1, respectively, again confirming negatively impacted quality of life. These questionnaires all suggest some level of burden on skin-specific disease, but larger scale studies with quality of life as the primary outcome are needed.

Conclusion

Inflammatory, granulomatous, scarring, and pigmentary skin and hair diseases that are specific to or more common in skin of color patients have been shown to significantly and negatively impact the quality of life of these patients. Thus, examining the burden of disease on quality of life in the skin of color patients is important, especially when many conditions may be improperly labeled as purely aesthetic. Health-related quality of life studies play a pivotal role in highlighting the psychosocial effects of disease that at times may even be greater than the physical impact of the disorder. As healthcare providers, we can utilize quality of life

research to assure that we are not underestimating disease burden and treating single facets of multifaceted disease in order to provide complete care. In addition, we may be able to use these instruments to provide data for improved advocacy for the health coverage of some of these disorders.

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