Am J Clin Dermatol (2013) 14:489–495
DOI 10.1007/s40257-013-0037-5

ORIGINAL RESEARCH ARTICLE

Quality of Life in Family Members of Vitiligo Patients: A Questionnaire Study in Saudi Arabia

**Ghada A. Bin Saif · Amal O. Al-Balbeesi ·
Rawan Binshabaib · Deema Alsaad · Shawn G. Kwatra ·
Abdullateef A. Alzolibani · Gil Yosipovitch**

Abstract

Background Many dermatologic disorders are known to adversely affect quality of life (QoL) in close relatives or partners of patients; however, it is unknown whether vitiligo impacts the QoL of family members.

Objective The aim of this study was to identify the level and domains in which the QoL of partners/relatives of patients with vitiligo are affected by the disease.

Methods A total of 141 patients with vitiligo, along with their family members, were recruited to complete validated QoL questionnaires, including the Dermatology Life Quality Index (DLQI) and the Family Dermatology Life Quality Index (FDLQI).

Results Family member QoL was affected in 129 (91.5 %) of subjects. Mean FDLQI score was 10.3 ± 6.4 standard deviation. Higher FDLQI score (greater impairment in QoL) was significantly associated with male patients, a shorter duration of disease, and higher educational levels in family members. The most affected FDLQI items in order of decreasing incidence were emotional impact, burden of care, impact on the physical well-being of the family member, problems due to the reaction of others in response to the patient's skin appearance and effect on social life. Overall FDLQI score and the number of items affected correlated with overall patient DLQI score ($p < 0.001$, $r = 0.56$ and $p < 0.001$, $r = 0.53$, respectively).

Conclusions Vitiligo has a major impact on the QoL of family members of patients and often significantly impairs many aspects of their lives. Educational and supportive programs are recommended for family members of vitiligo patients who are at an increased risk for QoL impairments.

1 Introduction

Vitiligo has a profound impact on the quality of life (QoL) of patients [1–3]. Disease visibility, the chronic and unpredictable nature of the disease, and lack of uniform effective therapy challenge patients' ability for social adaptation and psychological well-being [1]. Indeed, vitiligo patients may suffer from emotional and social sequelae of their condition, including low self-esteem, depression, social anxiety, stigmatization and rejection by others [4]. Those with the condition often rely heavily on support from family members/partners to overcome these psychosocial

---

G. A. Bin Saif (✉)
Department of Dermatology, College of Medicine, King Saud University, P.O. Box 54753, Riyadh 11524, Kingdom of Saudi Arabia
e-mail: gbinsaif@ksu.edu.sa

A. O. Al-Balbeesi · R. Binshabaib · D. Alsaad
Department of Dermatology, College of Medicine, King Saud University, Riyadh, Kingdom of Saudi Arabia

S. G. Kwatra
Department of Dermatology, Johns Hopkins Hospital, Baltimore, MD, USA

A. A. Alzolibani
Department of Dermatology, College of Medicine, Qassim University, Buraydah, Saudi Arabia

G. Yosipovitch
Department of Dermatology, Wake Forest School of Medicine, Winston-Salem, NC, USA

G. Yosipovitch
Department of Neurobiology and Anatomy, Wake Forest School of Medicine, Winston-Salem, NC, USA

G. Yosipovitch
Department of Regenerative Medicine, Wake Forest School of Medicine, Winston-Salem, NC, USA

obstacles. Lack of this crucial social support is an important predictor of poor physical and psychological functioning among patients with chronic skin disorders [5–9].

Certain dermatologic disorders have also been shown to adversely affect the QoL of a patient's family members [10–14]. Thus, the aim of the present study was to identify the level and specific domains in which the lives of family members of vitiligo patients are affected by the disease. We also sought to identify those at greater risk of impairment and to examine the correlation between family member and patient QoL.

2 Subjects and Methods

This prospective study was approved by the Institutional Review Board at the College of Medicine, King Saud University. It has therefore been performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments. All volunteers provided written informed consent and were free to withdraw from the study at any time.

Patients with vitiligo along with their partners/relatives were consecutively recruited from the dermatology outpatient clinics of the King Khalid University Hospital. Patients were included if they were diagnosed as having vitiligo without any other significant illness or disability. Inclusion criteria for family members were age greater than 18 years, having a close relationship with the patient, and living in the same household. Partners and relatives were excluded if they reported having any skin diseases or other significant illness that impaired their QoL, in order to avoid confusion of that impact with dermatology-related QoL.

Information was collected from the participants through separate validated Arabic-version questionnaires administered to patients and family members. The effect of vitiligo on patient QoL was measured using the Dermatology Life Quality Index (DLQI) [15, 16]. The effect of vitiligo on family member QoL was measured using the Family Dermatology Life Quality Index (FDLQI) [17]. Both scales had a scoring range from 0 to 30, with higher scores representing greater impairment in QoL. A score of 0–1 on the FDLQI was interpreted as having no effect at all on family member QoL. Patients agreeing to participate in the study who presented by themselves filled out patient-specific questionnaires and were given an envelope containing a questionnaire for a family member. The patients were asked to give the envelope to their family members and have the questionnaire returned or faxed back within 1 week.

2.1 Statistical Analysis

All analyses were performed using Predictive Analytics Software (PASW) version 18 (SPSS-IBM, Chicago, IL, USA). Descriptive statistics for quantitative variables were presented as mean ± standard deviation (SD). The significance of differences was assessed using an independent *t* test for continuous variables and Chi-square test for categorical variables. Analysis of variation (ANOVA) with post-hoc analysis was used to determine significance between groups. Statistical significance was set at $p < 0.05$.

3 Results

Of the 150 patients and family members/partners invited for the study, six declined to participate for personal reasons or because a family member was not willing to fill out the questionnaire. Three more were later dropped from the analysis after finding that the family member's age was not greater than 18 years. The final analysis was carried out on data from 141 (94 %) patients and their family members. The ages of vitiligo patients ranged between 17 and 70 years (mean = 30.3 years), while family members ranged between 18 and 61 years of age (mean = 33.2 years). Family members included 59 parents (27 men, 32 women), 45 spouses (26 men, 19 women), 20 sons or daughters (14 men, 6 women) and 17 other relatives (5 men, 12 women). Further demographic information of the study participants is displayed in Table 1.

3.1 Dermatology Life Quality Index (DLQI) Scores in Vitiligo Patients

Overall, 127 (90.1 %) patients described impairment in QoL (represented by a score ≥ 2). Patients had a mean DLQI of 9 ± 6.5 SD, with a range of 0–25.

3.2 Presence of Family Dermatology Life Quality Index (FDLQI) Impairment in Family Members of Vitiligo Patients

Family member FDLQI questionnaires were first analyzed by separating scores into two groups: a score of 0–1 representing no impairment to a family member's QoL, and a score of ≥ 2 representing impairment in family member QoL. Family member QoL was affected in 129 (91.5 %) subjects.

Vitiligo more often resulted in impairment in FDLQI if the affected patient was male (100 %) as compared with female (83.8 %; $p < 0.001$). Widowed or divorced family members were affected more (100 %) as compared with married (94.7 %) and single (76.9 %) family members ($p = 0.04$). Higher educational level of family members was also associated with a greater chance for impairment in FDLQI ($p < 0.001$).

Finally, differences were noted in the frequency of involvement of various family members. Daughters/sons

Table 1 Demographic data of study participants

Characteristic	Patients [*n* (%)]	Family members [*n* (%)]
Age, years (mean ± SD)	30.3 ± 13	33.2 ± 10.1
Gender		
Male	69 (48.9)	72 (51.1)
Female	72 (51.1)	69 (48.9)
Marital status		
Married	67 (47.5)	112 (79.4)
Single	68 (48.2)	25 (17.7)
Divorced/widowed	6 (4.3)	4 (2.8)
Educational status		
Primary or less	11 (7.8)	10 (7.1)
Middle/high school	41 (29.1)	48 (34.0)
Diploma/degree	77 (54.6)	67 (47.5)
Higher education	12 (8.5)	16 (11.3)
Disease duration, years (mean ± SD)	4.5 ± 3.1	
Exposed area involvement		
Involved	119 (84.4)	
Not involved	22 (15.6)	
Type of relation		
Parent		59 (41.8)
Son/daughter		20 (14.1)
Spouse		45 (31.9)
Other (sibling, grandparent, grandchild, cousin)		17 (12.1)

were the most affected (95 %), followed by spouses (91.1 %), parents (90.2 %), and other family members (84.2 %). No association was found between family member age or visibility of the lesion with FDLQI impairment.

3.3 Degree of FDLQI Impairment in Family Members of Vitiligo Patients

FDLQI scores for the overall scale ranged from 0 to 26 (mean score 10.3 ± 6.4 SD), with a greater score corresponding to more significant impairment in QoL.

FDLQI score was higher if the affected patient was male (mean score 12.5) compared with female (mean 8.2; $p < 0.001$). Patients who were widowed or divorced had relatives with significantly higher FDLQI scores (mean 16.5) compared with those who were married (mean 11.2), with the lowest FLDQI scores seen in relatives who were single (mean 8) [$p = 0.001$]. Greater patient and family member educational levels were associated with a higher FDLQI score (mean scores for patients with primary, middle, university, and higher education were 6, 9, 11, and 16.1, respectively; mean scores for family members with primary, middle, university, and higher education were 7, 9.5, 12, and 15, respectively) [for patients, $p = 0.02$; for family members, $p = 0.01$]. Longer disease duration corresponded to lower FDLQI scores (mean scores of patients with disease that lasted months vs. years were 13 vs. 9; $p = 0.046$). We also noted differences in mean FDLQI scores among different types of family members, with patient's spouses being the most affected (mean 11.53 ± 6.81), followed by daughters/sons (mean 10.6 ± 5.86), parents (9.24 ± 6.8), and other family members (9.2 ± 8.1). No association was found between family member age or visibility of skin lesions and the FDLQI score.

3.4 Total Number of FDLQI Items Affected

Mean total number of FDLQI items affected (0–10) was 6.17 ± 6.00 SD. More items in the FDLQI were affected if the patient was a male (mean 7.1) as compared with female (mean 5.3; $p < 0.001$). Patients and relatives who were widowed or divorced had a greater number of items affected as compared with married relatives, with singles again being the least affected (for patients, $p = 0.04$; for relatives, $p = 0.01$). The higher the patient and family member's educational level, the greater the number of items affected on the FDLQI (for patients, $p = 0.02$; for relatives, $p = 0.003$). No relationship was observed between the age or visibility of the skin lesions and the total number of FDLQI items affected.

3.5 FDLQI Individual Item Score Distribution

The mean scores for FDLQI individual items (range 0–3) were analyzed; the highest scoring items were found to be emotional impact (1.75), burden of care (1.38), impact on the physical well-being of the family member (1.15), problems due to the reaction of others in response to the patient's skin appearance (1.1), effect on social life (1.04), and effect on personal relationships (0.85) [Fig. 1].

Using the percentage (out of 141) responding positively (combining the answer choices corresponding to 'a little', 'quite a lot', and 'very much'), the most frequently reported FDLQI items were emotional impact (91.5 %), burden of care (75.9 %), impact on physical well-being of the family member (68.8 %), problems due to the reaction of others in response to the patient's skin appearance (66 %), effect on social life (63.8 %), and extra household expenditure (56.7 %) [Fig. 2].

3.6 Factors Affecting FDLQI Score Distribution

Scores for individual FDLQI items (range 0–3) were affected by the following social and medical factors.

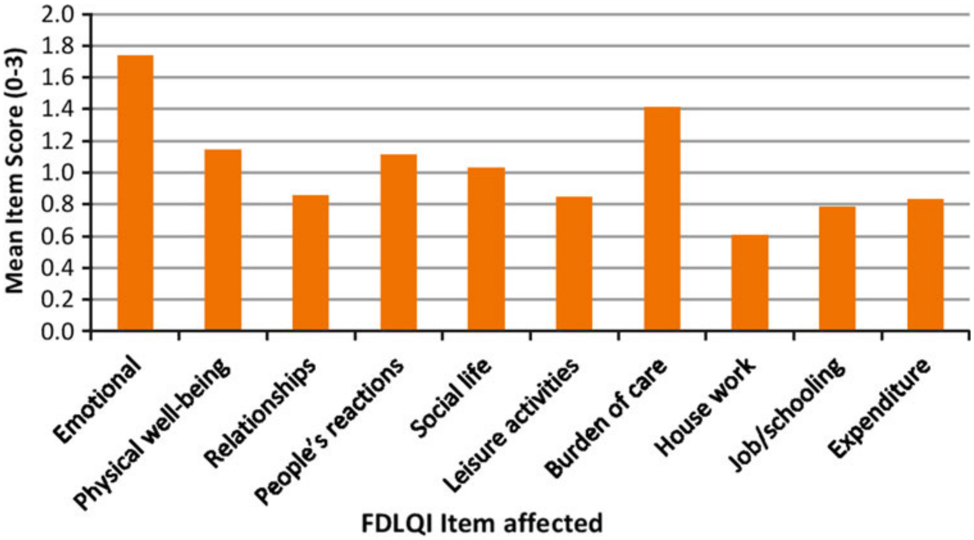

Fig. 1 Mean Family Dermatology Life Quality Index (FDLQI) scores for individual items

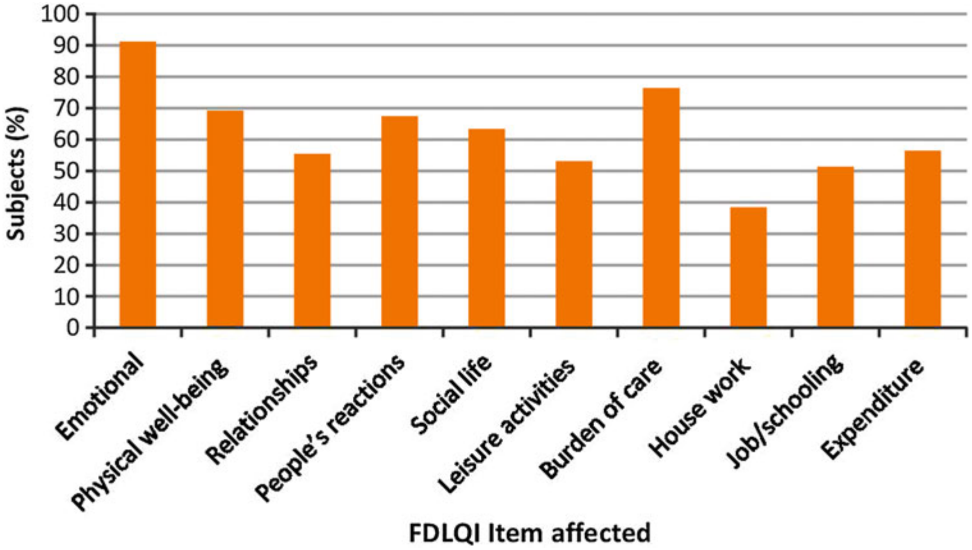

Fig. 2 Percentage of family members reporting different aspects of quality of life affected on the Family Dermatology Life Quality Index (FDLQI)

3.6.1 Gender of Family Member

Female family members had significantly greater FDLQI scores (mean 1.2) than men (mean 0.8) in the area of social life only ($p = 0.03$). No significant gender differences were found in the other domains.

3.6.2 Type of Relationship

Spouses were affected more than other family members in their emotional ($p = 0.01$) and physical well-being ($p = 0.02$), personal relationship ($p = 0.01$), and in their jobs/schooling ($p = 0.03$). Daughters/sons were affected more than other family members regarding extra household work ($p = 0.03$). Parents were affected more than others by extra household expenditure ($p = 0.02$).

3.6.3 Family Member Marital Status

Widowed and divorced family members had a greater emotional impact (mean 2) than married (mean 1.5) or single (mean 1.3) relatives [$p = 0.01$], while married family members had a higher burden of care (mean 1.47) than those who were single (mean 1.1), or widowed and divorced (mean 0.5) [$p = 0.04$].

3.6.4 Family Member Educational Level

We examined the effect of educational level and noted that a greater educational level of the relative/partner was associated with a higher impairment in FDLQI in the following domains: physical well-being ($p = 0.02$), personal relationships ($p = 0.01$), problems due to the reaction of others in response to the patient's skin appearance ($p = 0.04$), leisure activities ($p = 0.04$), burden of care ($p = 0.02$) and extra household expenditure ($p = 0.003$).

3.6.5 Disease Duration

By comparing different QoL aspects with the length of time patients had been diagnosed with vitiligo, we noted that longer disease duration had a decreased impact on family QoL in the following items: problems due to the reaction of others in response to the patient's skin appearance ($p = 0.03$), effect on leisure activities ($p = 0.01$), burden of care ($p = 0.04$), extra housework ($p = 0.01$), and effect on job/schooling ($p = 0.002$).

3.6.6 Visibility of the Lesions

Problems due to the reaction of others in response to the patient's skin appearance ($p = 0.049$) and the effect on social life ($p = 0.01$) affected the individual more if vitiligo involved exposed sites compared with non-exposed sites.

3.7 Relationship of Patient DLQI to FDLQI

A statistically significant correlation was noted between overall patient DLQI score and overall FDLQI score of family members ($p < 0.001$; $r = 0.56$). There was also a statistically significant correlation between total patient DLQI score and the number of items affected in the FDLQI ($p < 0.001$; $r = 0.53$).

4 Discussion

Patients with visible and often disfiguring skin disorders, such as vitiligo, may experience a distorted body image and experience significant psychosocial morbidity. Moreover, this impact may also affect family members. The results of the present study represent the first documentation of the secondary impact of vitiligo on the lives of family members and partners of these patients.

Basra et al. first formally identified the ways in which the lives of family members of patients with skin diseases are affected and found the most influenced domains to be emotional impact and burden of care [17, 18]. Our findings are consistent with these results and confirm emotional impact and burden of care to be the most influenced aspects of QoL in partners/family members of vitiligo patients.

The results of the present study also identify specific factors that influence the risk for impairment of QoL in family members. In particular, patients and family members with higher educational levels experienced greater impairments in QoL as compared with those that were less educated. This interesting finding is in direct contrast to conventional thinking that higher educational levels are associated with increased health-related QoL (HRQoL). For example, a recent study examining HRQoL associated with common medical conditions (e.g. diabetes mellitus, heart disease and asthma) found that patients with a higher educational level had significantly increased HRQoL [19]. Since educational levels are also highly associated with socioeconomic status, this increase in HRQoL is likely due, at least in part, to better access to resources to aid in disease management. In contrast, vitiligo is a benign disease (without a uniform effective therapy) with most of its impact on patient and family member QoL derived from psychosocial consequences of the disease. Thus, increased educational levels in these patients and their family members may result in a decrease in QoL that was observed in our study since they do not have a significant advantage in managing their disease (unlike patients with other chronic medical conditions), while suffering from heightened awareness of the psychosocial implications of vitiligo. However, the Porter et al. studies in the US showed that vitiligo patients with lower socioeconomic status suffered more from psychosocial implications than others did, perhaps due to lower self-esteem. Specific cultural differences between Western and Middle-Eastern societies may play a role here [20, 21].

Male gender was a patient-specific characteristic associated with a greater impairment in partner/family member QoL. Previous studies assessing gender differences and the effect of chronic skin disease showed that women have significantly increased overall impairment of QoL as compared with men in many skin diseases, including vitiligo, psoriasis, and atopic eczema [22–25]. In addition, individual FDLQI item analysis revealed that women family members had a significantly greater FDLQI item score than men in the area of social life. The observed findings may be specific to Saudi Arabian culture since men may play a more dominant role in the family setting.

Another patient-specific characteristic associated with a greater impairment in partner/family member QoL includes a shorter disease duration. This finding is expected as prolonged disease enhances the partner/family members' abilities to adjust and acquire coping skills to better deal with the patient's disease. In particular, longer disease duration had a significantly lower impact on the spouse/family member QoL in the following domains: problems due to the reaction of others in response to the patient's skin appearance, effect on leisure activities, burden of care, extra housework, and effects on job/schooling.

Deterioration in quality of family life was also found to be more correlated to a patient's QoL than to disease visibility. This is consistent with findings in psoriasis patients in that the psychological distress of a patient with psoriasis is related more to the level of psychological distress in their partner than to the objective severity of the disease [13, 14]. Furthermore, the impact of atopic eczema on family member QoL was related to patient QoL as well as to the clinical severity of the patient's disease [12].

The effect of vitiligo on family member QoL was significantly higher in the present study as compared with a smaller study by Basra et al. of patients with non-inflammatory skin conditions (including vitiligo) [17]. Moreover, the family impact we found of vitiligo is similar to that of the severe cutaneous disorder, recessive dystrophic epidermolysis bullosa in both the degree of impairment (epidermolysis bullosa mean FDLQI score was 9.8) and the domains affected [26]. Higher FLDQI scores in our study as compared with other diseases in the literature might be due to cultural differences in the experience of skin diseases and the perception of disability [17]. In particular, Saudi Arabia has distinctive social, religious and cultural factors that may influence a unique family member reaction to disease. In addition, the majority of the Saudi population is Fitzpatrick skin type IV and V, and it has been proven that vitiligo in darker skin individuals is associated with greater social and psychological implications for patients with the disease [2, 27, 28].

The last few years have seen psychosocial outcome measures receive an increasing amount of attention from physicians and researchers. These measures will aid clinicians in better understanding and gauging the impact of skin diseases, including vitiligo, and help to better capture appropriate treatment outcomes from both the patient and family member perspective. The strong relationship detected between vitiligo patients' QoL and family member QoL in the current study confirms that QoL of both the vitiligo patient and his/her family members are related psychosocial constructs. This highlights the need for treating physicians to simultaneously gauge the impact of vitiligo on a person's QoL as well as to consider the effects it may have on family members. However, this study has the potential for selection bias as patients were recruited from a single academic center. This hospital-based population may not be representative of the target population. Moreover, vitiligo impact on the family QoL must be reassessed in other ethnic groups.

5 Conclusion

Our data indicates that vitiligo has a major impact on the QoL of family members of patients and often significantly impairs many aspects of their lives. Educational and supportive programs are recommended for family members who are at higher risk for QoL impairment. Future studies should investigate supportive treatment that might aid in improving family member QoL.

Acknowledgments *Funding* This project was supported by the College of Medicine Research Center, Deanship of Scientific Research, King Saud University. The authors' work was independent of the funder.

Conflicts of interest The authors have no conflicts of interest that are directly relevant to the content of this study.

References

1. Parsad D, Dogra S, Kanwar AJ. Quality of life in patients with vitiligo. Health Qual Life Outcomes. 2003;1:58.
2. Al Robaee AA. Assessment of quality of life in Saudi patients with vitiligo in a medical school in Qassim province, Saudi Arabia. Saudi Med J. 2007;28:1414–7.
3. Karelson M, Silm H, Kingo K. Quality of life and emotional state in vitiligo in an Estonian sample: comparison with psoriasis and healthy controls. Acta Derm Venereol. 2012. doi:10.2340/00015555-1520.
4. Papadopoulos L, Bor R, Legg C. Coping with the disfiguring effects of vitiligo: a preliminary investigation into the effects of cognitive-behavioural therapy. Br J Med Psychol. 1999;72:385–96.
5. Stangier U, Ehlers A, Gieler U. Measuring adjustment to chronic skin disorders: validation of a self-report measure. Psychol Assess. 2003;15:532–49.
6. Trask PC, Paterson AG, Hayasaka S, et al. Psychosocial characteristics of individuals with non-stage IV melanoma. J Clin Oncol. 2001;19:2844–50.
7. Koo JYM, Lee CS, editors. Psychocutaneous medicine. New York: Marcel Dekker; 2003.
8. Lu Y, Duller P, van der Valk PGM, Evers AWM. Helplessness as predictor of stigmatization in patients with psoriasis and atopic dermatitis. Dermatol Psychosom. 2003;4:146–50.
9. Evers AW, Kraaimaat FW, van Lankveld W, et al. Beyond unfavorable thinking: the Illness Cognition Questionnaire for chronic diseases. J Consult Clin Psychol. 2001;69:1026–36.
10. Lawson V, Lewis-Jones MS, Finlay AY, et al. The family impact of childhood atopic dermatitis: the Dermatitis Family Impact questionnaire. Br J Dermatol. 1998;138:107–13.
11. Titman PS, Barker C, Smith CH. The psychological impact of chronic eczema on children and their families. Br J Dermatol. 2001;145(Suppl.59): 128–9.
12. Ben-Gashir MA, Seed PT, Hay RJ. Are quality of family life and disease severity related in childhood atopic dermatitis? J Eur Acad Dermatol Venereol. 2002;16:455–62.
13. Richards HL, Chong SLP, Mason DL, Griffiths CEM. The impact of psoriasis on healthy partners of patients with psoriasis. Br J Dermatol. 2002;147(Suppl.62):40.
14. Eghlileb AM, Davies EE, Finlay AY. Psoriasis has a major secondary impact on the lives of family members and partners. Br J Dermatol. 2007;156:1245–50.
15. Finlay AY, Khan GK. Dermatology Life Quality Index, a simple practical measure for routine clinical use. Clin Exp Dermatol. 1994;19:210–6.
16. Lewis VJ, Finlay AY. 10 years experience of the Dermatology Life Quality Index. J Invest Dermatol Symp Proc. 2004;9:169–80.
17. Basra MKA, Sue-Ho R, Finlay AY. The Family Dermatology Life Quality Index: measuring the secondary impact of skin disease. Br J Dermatol. 2007;156:528–38.

18. Basra MK, Finlay AY. The family impact of skin diseases: the greater patient concept. Br J Dermatol. 2007;156:929–37.
19. Mielck A, Reitmeir P, Vogelmann M, Leidl R. Impact of educational level on health-related quality of life (HRQL): results from Germany based on the EuroQol 5D (EQ-5D). Eur J Public Health. 2013;23:45–9.
20. Porter J, Beuf AH, Nordlund JJ, Lerner AB. Psychological reaction to chronic skin disorders: a study of patients with vitiligo. Gen Hosp Psychiatry. 1979;1:73–7.
21. Porter JR, Beuf AH, Lerner A, Nordlund J. Psychosocial effect of vitiligo: a comparison of vitiligo patients with "normal" control subjects, with psoriasis patients, and with patients with other pigmentary disorders. J Am Acad Dermatol. 1986;15:220–4.
22. Borimenjad L, Yekta ZP, Nusrabadi AN, Firooz A. Quality of life with vitiligo: comparison of male and female Muslim patients in Iran. Gend Med. 2006;3:124–30.
23. Holm EA, Esmann S, Jemec GB. Does visible atopic dermatitis affect quality of life more in women than in men? Gend Med. 2005;1:125–230.
24. Zachariae R, Zachariae C, Ibsen HH, et al. Psychological symptoms and quality of life of dermatology outpatients and hospitalized dermatology patients. Acta Derm Venereol. 2004; 84:205–12.
25. Gelford J, Feldman S, Stern R, et al. Determinants of quality of life in patients with psoriasis: a study from US population. J Am Acad Dermatol. 2004;51:704–8.
26. Sampogna F, Tabolli S, Di Pietro C, et al. The evaluation of family impact of recessive dystrophic epidermolysis bullosa using the Italian version of the Family Dermatology Life Quality Index. J Eur Acad Dermatol Venereol. 2012. doi:10.1111/j.1468-3083.2012.04682.x.
27. Al-Mubarak L, Al-Mohanna H, Al-Issa A, et al. Quality of life in Saudi vitiligo patients. J Cutan Aesthet Surg. 2011;4:33–7.
28. Linthorst Homan MW, Spuls PI, de Korte J, et al. The burden of vitiligo: patient characteristics associated with quality of life. J Am Acad Dermatol. 2009;61:411–20.