






POSITION STATEMENT

Quality of life measurement in occupational skin diseases. Position paper of the European Academy of Dermatology and Venereology Task Forces on Quality of Life and Patient Oriented Outcomes and Occupational Skin Disease

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Abstract

The European Academy of Dermatology and Venereology (EADV) has started the 'Healthy Skin @ Work' campaign aimed to raise awareness among the public and EU authorities on the frequency and impact of occupational skin diseases (OSDs). The EADV Task Forces (TFs) on Quality of Life and Patient Oriented Outcomes (QoL/PO) and on OSD present their mutual position statement on QoL assessment in OSDs. The EADV TFs recommend the use of the DLQI as a dermatology-specific instrument and SF-36 as a generic instrument in health-related (HR) QoL studies on OSDs. The OSD-specific questionnaire, LIOD, is not recommended for general use in its present form because of its three months recall period. The EADV TFs discourage the use of non-validated and of non-validated modifications of previously validated HRQoL instruments. The EADV TFs wish to encourage research into: the HRQoL impact of OSDs other than occupational contact dermatitis and hand eczema; comparisons between the effects of different treatments and other interventions on HRQoL in OSDs; and into the HRQoL impairment of patients with OSDs from different countries, and with different provoking factors, to predict if the results of successful therapeutic and educational interventions may be generalized across countries and between occupations.

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Conflicts of interest

AYF is joint copyright owner of the DLQI, CDLQI, IDQoL, DFI, FDLQI, TQoL, FROM-16, PFI, MLCDP and other quality-of-life measures: Cardiff University and AYF receive royalties from the use of these measures. AYF has received honoraria

for advisory boards: Sanofi, Novartis, Napp, Galderma. JCS reports personal fees from Abbvie, personal fees from Leo Pharma, personal fees from Novartis, personal fees from Pierre-Fabre, personal fees from Menlo Therapeutics, personal fees from Sienna Biopharmaceuticals, personal fees from Trevi, personal fees from Janssen, personal fees from Sunfarm, personal fees from Elli-Lilly, personal fees from Berlin-Chemie Mennarini, personal fees from Merck, personal fees from Regeneron, personal fees from Sanofi-Genzyme, personal fees from Amgen, personal fees from Boehringer Ingelheim, personal fees from Galapagos, personal fees from InflaRX, personal fees from Pfizer, personal fees from UCB, personal fees from Incyte, personal fees from Helm, outside the submitted work. MG has received consulting fees or fees for lectures from Novartis and Sanofi. AB has received travel grants or acts as an ad hoc consultant for Abbvie, Almirall, Galderma, Janssen, Lilly, Leo Pharma, Novartis, Sanofi and UCB. MSS is joint copyright owner of TQoL, FROM-16, PFI and MLCD: Cardiff University and MSS receive royalties from the use of these measures. MSS has received unrestricted educational grant from Celgene, European Hematology Association, GSK and Centre for Innovative Regulatory Science (CIRS). Other authors reported no conflicts of interests.

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Introduction

The European Academy of Dermatology and Venereology (EADV) has created the 'Healthy Skin @ Work' campaign aimed to raise awareness among the public and EU authorities on the frequency and impact of occupational skin diseases (OSDs) and to create a prevention service system that interlocks and builds upon each other for the benefit of exposed individuals in high-risk professional environments throughout the EU. The main focus is on occupational irritant and allergic contact dermatitis, among the most frequent occupational diseases worldwide, affecting in particular healthcare workers, hairdressers/aestheticians, metal and construction workers. Another main aim has been the definition and recognition of occupational skin cancer and precancerous lesions, namely actinic keratosis, basal cell and squamous cell carcinoma. These are increasingly recognized in many countries as being occupation-related, and hence, the patient may be eligible for compensation. In addition to the provision of a national health service or statutory health insurance, most European countries have implemented insurance schemes specifically geared at occupational diseases.¹ In some countries, all employees are insured for occupational disease, and insurance companies/institutions provide data on occupational diseases to the national registers.²

There are reports of effective individual prevention programmes in OSDs.^{3,4} Without effective preventive measures, OSDs may become chronic skin conditions which may then lead to changes in occupation or even exclusion from the labour market, through unemployment or by being in receipt of a disability pension.^{5,6} The negative impact of OSD may not be limited to change or reduction in working activities, but also have wide repercussions throughout many aspects of a person's life. The most popular dermatology-specific quality-of-life (QoL) instrument, the Dermatology Life Quality Index (DLQI), has one item related to the impact of skin disease on work.⁷ The

number of publications on QoL in dermatology has constantly grown each year over the past 20 years.⁸ There are many reasons why the use of QoL assessment may be beneficial in routine clinical practice, as reported by the EADV Task Force (TF) on Quality of Life and Patient Oriented Outcomes (QoL/PO).⁹ The aim of this literature review and position statement is to focus on the key findings of QoL studies in OSDs, to analyse methods of QoL assessment in OSDs, including identifying frequently made mistakes, and to suggest topics for future studies in this field.

Methods

Members of the EADV TFs on QoL/PO and OSD were invited to participate. A working group consisting of 17 EADV members was formed. A literature search was performed using the PubMed database, which was searched from 1970 to 15 November 2019 using the key word combinations: 'occupational skin diseases and quality of life'. All publications written in English or those having English abstracts were considered. All those who volunteered were allocated a section of the identified articles to review.

Exclusion criteria:

- 1 Reviews, guidelines, conference reports
- 2 Studies not on skin diseases
- 3 Studies with no QoL assessment component
- 4 Studies not on OSDs
- 5 Non-English articles without an abstract in English

Articles where health related (HR) QoL was studied in OSDs and other diseases but results on OSDs were not presented and/or discussed separately were also excluded.

All publications were independently assessed by two co-authors. The assessments were compared and discrepancies discussed and resolved. The remaining publications were analysed; information concerning QoL assessment was recorded using a 'data extraction template' that included the name of QoL

instruments used, diagnosis, numbers of patients and their occupations and the main results related to QoL. The EADV TF on QoL/PO recommends using the word 'quimp' (quality-of-life impairment)¹⁰ in routine clinical work and research,¹¹ and the word has been used in this article. The terms QoL and HRQoL are used interchangeably throughout the paper.

Results

From the 369 articles identified in the literature search, 328 were excluded based on the exclusion criteria, leaving 41 publications for the final analysis.¹²⁻⁵² The list of included publications and their characteristics are given in Table S1. The data identified on HRQoL assessment in patients with OSDs only concerned occupational irritant contact dermatitis, occupational allergic contact dermatitis and occupational hand eczema.

HRQoL instruments used in the studies on OSDs

The DLQI, a dermatology-specific HRQoL instrument, was used in 32 (78%) of the 41 studies (Table 1). The generic HRQoL

instrument SF-36 was used in nine (22%) studies. The Life Quality Index Occupational Dermatoses (LIOD) questionnaire was used three times. Other instruments were used in two or less studies each (Fig. 1).

HRQoL in OSDs and the general population

All SF-36 domains and dimensions scores of occupational hand eczema patients were impaired (reduced) as compared with the general population in a German study.²³ Another study from Germany showed that all SF-36 domains (except physical functioning) were more impaired in a group of patients with occupational dermatitis compared to the general population. In contrast, the physical functioning domain was significantly less impaired.²⁷ In an Australian study of hand eczema patients, the scores in all domains of the SF-36 were comparable to the population norm scores, except for the social functioning domain, where the score was significantly lower (reflecting better QoL) for the occupational contact dermatitis group.²⁵ Nursing staff with hand eczema recorded a

Table 1 The Dermatology Life Quality Impact scores in patients from different countries and with different diagnosis

Country	Diagnosis	Mean DLQI score	Reference
India	Occupational contact dermatitis	15.8 ± 5.9 – all patients before treatment 16.9 – farmers 14.6 – constructive workers 13.9 – housewives 7.1 ± 5.1 – all patients after treatment	12
India	Occupational contact dermatitis	13.0 – before treatment 7.0 – after treatment	44
UK	Occupational contact dermatitis	6.6	34
Australia	Occupational contact dermatitis	10	26
Germany	Occupational contact dermatitis	8.9	14
Australia	Occupational contact dermatitis	4.5 (follow-up)	25
Denmark	Occupational contact dermatitis	5.0 (follow-up)	47
Brazil	Occupational allergic contact dermatitis	11.9	48
UK	Latex allergy	17.9 – before diagnosis 10.9 – after diagnosis	31
Germany	Occupational hand eczema	10.7 – before treatment 5.7 – after treatment	13
Germany	Occupational hand eczema	11.1	23
Germany	Occupational hand eczema	From 10.3 to 12.5 in different subgroups	46
Germany	Occupational hand eczema	10.9	49
Denmark	Occupational hand eczema	5.5	40
Germany	Occupational skin diseases (93.4% occupational hand eczema)	10.4 or 10.2 – at the beginning 5.5 – after intervention 5.5 – 12 months after intervention 5.0 – 3 years after intervention	21,24,42
Belgium	Contact dermatitis?	3.3 – operating nurses	33
India	Hand eczema	7.3 – cleansers 4.1 – nurses 3.6 – nursing auxiliaries	16
Denmark	Hand eczema	2.8–2.9 in different groups - at the beginning 2.1–2.4 in different groups (long-term follow-up: 45 months and 35 months, respectively)	18
Denmark	Hand eczema	1.2–2.0 in different groups after treatment	52

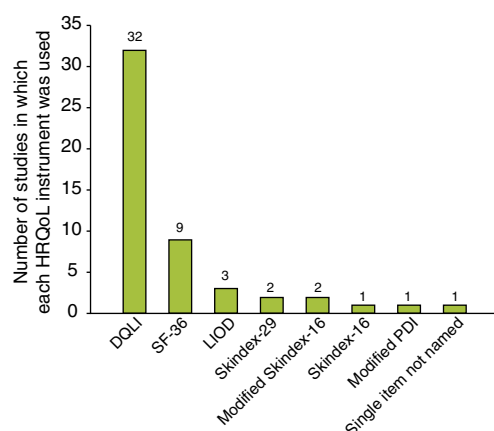


Figure 1 Use of health-related quality-of-life instruments in the studies on occupational skin diseases.

higher impact than population norms on all SF-36 domains except vitality and role emotional.³⁶

Impact of OSDs in different occupations

In a study from India, there was no statistical difference in mean baseline DLQI scores between people with various occupations.¹² After treatment, there was a 43.5% improvement in DLQI scores in construction workers, 55.2% in farmers, 43.4% in housewives and 80.0% improvement in healthcare workers. There was a statistically significant greater impairment in QoL in cleaners compared to nurses and nursing auxiliaries.¹⁶ There were higher mean DLQI scores (indicating greater QoL impairment) among operating nurses compared to female administrative employees.³³ Industrial workers reported impaired QoL on several items of modified Skindex-16 questionnaire.²⁹ Significantly higher DLQI scores were reported by patients with natural rubber latex allergy compared to patients with epoxy and rubber chemical allergy.⁴⁷ The HRQoL of patients with hand eczema was less impaired in a metropolitan population compared to that of a non-metropolitan group.¹⁹

HRQoL in OSDs and other skin diseases

The mean DLQI score in patients diagnosed with occupational allergic contact dermatitis was significantly higher than that in patients with occupational irritant contact dermatitis.¹² In a comparison between patients with contact dermatitis, atopic dermatitis, occupational dermatitis and other skin diseases, QoL was most impaired in the occupational dermatitis group.²²

Occupation-related allergic contact dermatitis was associated with worse QoL scores within the occupational impact and functioning scales of the modified version of Skindex-16. Subjects that had changed jobs because of allergic contact dermatitis had more severe QoL impairment than any other group analysed, with significantly worse scores on 17 of the 21 QoL items.³² In a

study with a low number of subjects, QoL in patients with occupational and non-occupation allergic contact dermatitis was not significantly different.⁴⁸

Other findings of HRQoL studies in OSDs

The patients with severe hand eczema threatened with job loss showed high levels of anxiety and depression, and severely impaired HRQoL.²³ The DLQI scores for participants who changed profession or left the labour market had increased at follow-up.²⁰ In a UK study of patients with occupational contact dermatitis, there was no significant correlation between age and DLQI score.³⁴ Direct costs for occupational hand eczema treatment were the same in patients with mild or moderate/severe disease severity, but their QoL was significantly different.⁴⁹ It was shown that being more knowledgeable about occupational hand eczema does not improve QoL.⁵⁰ Non-Caucasian subjects with OSDs reported significantly lower QoL scores (i.e. more impaired) than did Caucasians on all but one item within the functioning scale of a modified Skindex-16 questionnaire.²⁹

Impact of gender differences on HRQoL of patients with OSDs

Comparisons between male and female subjects with OSDs have shown no significant differences in their QoL scores.^{23,25,27,29,34} However, in one study females had significantly higher scores in the 'symptoms and feelings' category²³ while another study reported better general health²⁵, but a worse vitality score than males.^{25,27} Females also showed significantly more physical and emotional impairment than males in a study using Skindex-29.²⁷

Interventions to improve HRQoL in OSDs

In all interventional studies reviewed, an improvement of HRQoL was noted. For example, a study aimed to assess the efficacy of four weeks of 0.05% halometasone monohydrate in patients with occupational irritant and allergic contact dermatitis demonstrated significant improvement of QoL at week four.⁴⁴ Other studies on occupational skin diseases had follow-up periods from three weeks to five years.^{12,13,15,17,18,25,35,39,42,45,47,52} Significant QoL improvement was observed three weeks after a tertiary individual prevention programme that included dermatological therapy, detailed healthcare instruction and psychological treatment.¹³

Improvement of quimp was reported five months after the intervention that consisted of a single 20–30 min consultation with a trained dermatologist who educated the participants individually in skin protective behaviour and gave individual counselling based on work and home-related exposures.¹⁸ Improvement of HRQoL was seen one year after attendance at secondary individual prevention courses.^{35,39} Patients' HRQoL improved in the educational group at five-month follow-up in a study aimed to compare the effect of a secondary prevention programme (i.e. education on skin care and individual

counselling) to standard treatment in a group of healthcare professionals with hand eczema.⁵² There were no significant differences in change of QoL between the two groups at one-year follow-up in a study of patients with newly notified occupational hand eczema where group-based education about skin protective behaviour was compared to standard treatment.¹⁷ In a long-term patient management programme, with two years follow-up, the presence of occupational skin disease was a negative predictive factor for QoL improvement.¹⁵ A cohort of occupational contact dermatitis patients at five-year follow-up reported that their QoL generally remained impaired.²⁵

Discussion

In contrast to many other skin diseases, there have been numerous studies of patients with OSDs with long-term follow-up. It is therefore possible to assess the short- and long-term clinical course of OSDs and their impact on patients' QoL. Both treatment and educational programmes have been shown to be highly effective, resulting in long-lasting improvement of clinical signs and HRQoL. The results of these studies are potential sources of valuable information for the development and audit of national and international programmes on the prevention and management of OSDs. It is especially important in the context of the outbreak of contact dermatitis related to antiseptics and individual protection equipment use during COVID-19 pandemic. The use of the DLQI questionnaire in most of the studies has made it possible to compare their results, revealing distinct heterogeneity between countries and diagnoses. This may be because of different disease severities and occupations of the patients studied. Partly because of cultural differences, patients from different countries with the same diagnosis and disease severity may record different HRQoL scores.⁵³ Even where total QoL scores in patients from different countries are similar, there may be significant differences in individual QoL item scores.⁵⁴ There is a tendency for HRQoL scores in developing and non-European countries to suggest greater perceived impairment (Table 1). This was also previously noted in international studies on atopic dermatitis.^{55,56} The DLQI, a dermatology-specific instrument, may be more sensitive to change than the SF-36, a generic instrument, in occupational contact dermatitis patients.²⁵

The baseline mean DLQI scores of patients with occupational skin diseases in most of the studies reviewed were around 10. This is at the borderline meaning between 'moderate effect on life' and 'very large effect', according to the DLQI banding descriptor system.⁵⁷ In many countries, a DLQI score above 10 is a triggering parameter for prescription of systemic biological therapy in psoriasis, based on Finlay's concept of 'The Rule of Tens'.⁵⁸ The reduction of the DLQI scores (i.e. improvement) after treatment or educational interventions in most of the studies exceeded the minimal clinically important difference for the DLQI (four score points)⁵⁹, but did not reach the absolute score

level of 0 or 1, meaning 'no effect on patient's life',⁵⁷ that is a difficult to reach but important treatment goal.⁶⁰ It might be thought that patients who have changed their job or left the labour market because of occupational skin disease would experience HRQoL improvement but, counterintuitively, there is evidence for the opposite.^{20,32} This means that job change is not necessarily an optimal strategy for OSDs management and prevention.

The studies reviewed were focused on the most prevalent OSDs: occupational irritant contact dermatitis, occupational allergic contact dermatitis and occupational hand eczema.⁶¹ Therefore, future prospective QoL studies should consider other OSDs. In particular, such studies are important for the second main target of the Healthy Skin @ Work campaign – occupational skin cancer induced by UV solar radiation. There is a lack of studies comparing the HRQoL between patients with different occupations and diagnoses, and also evidence is limited on the influence of different provoking factors. It seems that occupation-related dermatitis and hand eczema generally cause more severe HRQoL impairment than non-occupational dermatitis and hand eczema, even in patients with the same occupation. The results of a study that compared HRQoL, clinical signs and skin barrier alterations in operating room nurses and female administrative employees unequivocally confirmed a predisposition of nurses to OSDs. It also raised the question of underdiagnosis of OSDs in the early stages and in cases where disease severity and quimp are low.³³

The most prevalent agents causing occupational irritant contact dermatitis are different between men and women.⁶¹ Women have a higher prevalence of positive patch test reactions to allergens.⁶² It may be partially explained by unequal gender representation in the various occupations. However, most of the studies did not report significant gender differences in QoL scores^{23,25,27,29,34} except in some domains.^{23,25,27} We speculate that apparently higher quimp in non-Caucasian subjects with OSDs²⁹ is based on cultural rather than on genetic-based differences.

In addition to well-validated instruments, such as the DLQI, SF-36 and Skindex-29, other instruments were used. However, in some publications numeric data on QoL scores were not presented or there was limited information on score changes, without clear data on the scores before and after interventions. The LIOD questionnaire, specific for OSDs, was rarely used and has the disadvantage of a 3-month recall period. Such a long recall period may introduce response bias, preclude frequent use⁶³ and make it inappropriate for many clinical trials. The Quality of Life in Hand Eczema Questionnaire (QOLHEQ) was developed and validated for patients with hand eczema⁶⁴ and may therefore be more sensitive to reflect QoL changes in this skin disease than generic instruments but up to now, studies to confirm that the QOLHEQ is indeed a good instrument for assessment of QoL in OSD are missing. Other instruments that were identified included the modified versions of the Skindex-16, Psoriasis

Disability Index (PDI) and an unnamed single item instrument. The EADV Task Force on QoL/PO recommends that only validated instruments should be used.^{65–67} Furthermore, modified versions of validated instruments should either not be used or be fully revalidated prior to their implementation. Clearly, numeric data on QoL scores should be provided in publications. Unless the scores of separate items of HRQoL questionnaires are reported, it is not possible to understand the impact of skin diseases on different aspects of HRQoL.^{65–71} In addition, it is important to present clear data on the occupations of patients with OSDs. The recommendations arising from this position paper are as follows:

- The EADV TFs urge researchers and practitioners to:
 - study quimp in OSDs other than occupational contact dermatitis and hand eczema (e.g. occupational skin cancer);
 - compare the effects of different treatments and other interventions on QoL in OSDs;
 - study quimp in patients with OSDs from different countries, and with different provoking factors, to predict if the results of successful therapeutic and educational interventions may be generalized across countries and between occupations.
- The EADV TFs recommend the use of the DLQI as a dermatology-specific instrument and SF-36 as a generic instrument in studies investigating the impact of OSDs on HRQoL. The OSD-specific questionnaire LIOD is not recommended for general use in its present form because of its 3-month recall period.
- The EADV TFs discourage the use of not validated and modified HRQoL instruments unless they have been completely revalidated prior to their implementation.

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Supporting information

Additional Supporting Information may be found in the online version of this article:

Table S1. Brief characteristics of included publications.