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## **Methods to improve the quality of life**

### **Position statement of the European Academy of Dermatology and Venereology Task Force on Quality of Life and Patient Oriented Outcomes**

Running head: Improvement of quimp beyond medicines

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***Conflict of interest***

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## **Abstract**

The pharmaceutical approach to skin disease has been hugely successful, but despite effective drugs being available and used, there are still vast numbers of people who continue to have some level of persisting skin disease and continue to experience quality of life (QoL) impairment. So the question that needs to be answered, while we await further advances in our drug-based armamentarium, is how can we improve patients' QoL, beyond drugs? A working group was formed from members of the EADV Task Force on QoL and Patient Oriented Outcomes. Participants were asked to suggest all the ways in which they considered patients' QoL may be improved beyond medicines. Four groups of management approaches that may improve QoL in dermatology were identified: interventions within the dermatology service (hospitalisation, multidisciplinary teams, patch testing and establishing relevant allergens and education), external services (corrective make-up, climatotherapy and balneotherapy), psychological (psychological intervention, cognitive therapy, hypnosis, support groups and others), lifestyle (lifestyle behavioural changes, religion and spirituality and music). The ultimate aim of therapy is to eradicate a disease in an individual and return the person's life to normal. But until the day comes when this has been achieved for every skin disease and for every patient there will be a need to support and assist many patients in additional non-pharmaceutical ways. These "adjuvant" approaches receive too little attention while dermatologists and researchers strive for better pharmacological therapy. The different ways in which patients may benefit have been reviewed in our paper, but the reality is that most have a very poor evidence base. The research challenges that we have to meet are to identify those approaches that might be of value and to provide evidence for their optimal use. In the meantime, clinicians should consider the use of these approaches where QoL remains impaired despite optimal use of standard therapy.

## **Introduction**

The pharmaceutical approach to skin disease has been hugely successful, but despite effective drugs being available and used, there are still vast numbers of people who continue to have some level of persisting skin disease and continue to experience quality of life (QoL) impairment. This provides a major challenge to all clinicians.

Over the last four decades, the understanding of the impact that skin disease has on the lives of those affected has dramatically increased. This has been facilitated by the development of many questionnaire methods to measure this impact. The associated education of the dermatology community about this aspect of skin disease has led to a spirit of enquiry by dermatologists to understand better their own patient's experiences, and use this information to inform better clinical decision making, in the interests of the patients. The comparison and assessment of new therapies now routinely includes reference to their relative impact on improving QoL.

This revolution in thinking trains a spotlight onto a major therapeutic challenge in dermatology: despite the range of available effective drugs being greatly superior now compared to fifty years ago, many people still need additional help. So the question that needs to be answered, while we await further advances in our drug-based armamentarium, is how can we improve patients' QoL, beyond drugs?

The presence of skin lesions and disease severity are the main drivers of health-related QoL (HRQoL) impairment in patients with skin diseases.<sup>1-5</sup> Therefore the prevention of skin diseases and of their relapses, effective treatment and skin care are the main strategies for QoL improvement. In many cases to have no impact of skin disease on their life, patients should be "clear" or "almost clear" from skin lesions. For example, patients with disseminated psoriasis need to achieve more than 90% improvement in psoriasis area and severity index (PASI) to have **no quimp**.<sup>6-8</sup> However in many skin diseases it is extremely difficult to reach 90% improvement or clearance. HRQoL encompasses many different aspects and it is theoretically possible to improve HRQoL, influencing specific aspects of a patient's life in addition to providing standard

treatment. In patients with skin disease, factors such as difficulties in social and leisure activities; difficulties in significant relationships with others, including partners, close friends, and/or relatives; embarrassment; self-consciousness; aggression and frustration may all influence the decision of patients to seek advice from a dermatologist.<sup>9</sup>

The aim of this review by the European Academy of Dermatology and Venereology (EADV) Task Force (TF) on Quality of Life and Patient Oriented Outcomes (QoL/PO) is to identify and present methods that may improve the HRQoL of patients, beyond medicines.

## **Methods**

A working group was formed from members of the EADV TF on QoL/PO. There were eight dermatologists, one psychologist, one epidemiologist and one pharmaco-epidemiologist with special interest in skin diseases in the working group. Participants were asked to suggest all the ways in which they considered patients' QoL may be improved beyond medicines. In addition a literature search was performed using the PubMed database, which was searched from 1980 to March 2020 using the key word combinations: "dermatology, quality of life". All publications written in English or those having English abstracts were considered. Additional searches were performed for ways that have been suggested to improve HRQoL: hospitalization, multidisciplinary teams, patch testing and establishing relevant allergens, education, corrective make-up, climatotherapy and balneotherapy, psychological interventions, lifestyle behavioral changes, religion and spirituality and music. This paper only presents methods whose efficacy has been described in published studies. The areas identified have been grouped into four main sections: Interventions within the dermatology service, External services, Psychological and Lifestyle (Table 1).

The EADV TF on QoL/PO recommends using the word "quimp"<sup>10</sup> (QoL impairment) in routine clinical work and research<sup>11</sup> and the word has been used in this article.

## **Management approaches that may improve QoL in dermatology**

## **Interventions within the dermatology service**

### ***Hospitalization***

Despite improvements in the facilities available and the quality of outpatient care, a core of patients remain for whom inpatient care is essential.<sup>12</sup> Patients who have extensive skin disease or are physically frail or disabled may find it difficult to cope with an outpatient topical regimen. Topical treatment for skin disease can be time-consuming, complicated, and laborious. The elderly, in particular, may require inpatient care to ensure rapid resolution of their skin condition. An inpatient stay offers a period of intensive treatment in a haven away from the public eye and from the stresses of everyday life. It also provides the opportunity to educate patients about their condition and treatment as well as provide social support.<sup>13</sup> Baseline Dermatology Life Quality Index (DLQI) scores for hospitalized patients with psoriasis were significantly higher (greater quimp) compared with the QoL of a cross section of psoriasis patients being managed in an outpatients' department. One week after discharge, the QoL of hospitalized patients had significantly improved and remained improved at three months follow-up.<sup>14</sup> Patients with psoriasis and severe eczema showed, overall, a significant decrease in quimp following inpatient treatment. The parameters over which most improvement was seen were those which were of most concern to the patients, i.e. their symptoms and their embarrassment.<sup>15</sup> The mean DLQI scores for all patients decreased after hospital admission in Cardiff (UK) and Miami (USA) in a trans-Atlantic comparative study of the effect of hospitalization on severe skin disease. Despite the differences in the health care systems, inpatient therapy remained an important and effective therapeutic option in both countries.<sup>16</sup>

### ***Multidisciplinary teams***

Multidisciplinary teams (MDT) including dermatology health care professionals (HCP) either in isolation or linked to other specialty teams<sup>17</sup> have been shown to improve QoL across a range of different dermatological diseases. Research has tended to focus on common inflammatory dermatoses such as psoriasis<sup>18-20</sup> and atopic eczema,<sup>21,22</sup> but has also focused on rarer dermatological diseases such as dermatitis artefacta.<sup>23,24</sup> Patients managed by a MDT show greater improvements in QoL than similar patients managed in general dermatology clinics, for both adult and (particularly) paediatric dermatology.<sup>25</sup>

In the management of patients with skin disease, some MDTs include psychologist support. Psychologists can provide a range of different techniques including educational, training programmes and cognitive behavioural therapy techniques. Where these techniques are applied in addition to basic dermatology care, there are significant improvements in QoL outcomes,<sup>18-22</sup> both for paediatric and adult MDT dermatology care.

Living with chronic skin disease may lead to psychosocial co-morbidities.<sup>23,24</sup> MDTs involving psychiatrists can significantly improve QoL as measured by the DLQI for patients with psoriasis and atopic dermatitis (AD).<sup>20,24</sup> Various outcome measures are used in MDT QoL research: the most commonly used QoL measure is the DLQI, but other measures include the dermatology specific Skindex-29, and disease specific QoL measures such as the Psoriasis Disability index (PDI) and the Quality of Life for Atopic Dermatitis (QoLIAD).<sup>18-22</sup> Where patients are managed by cross specialty MDTs (usually dermato-rheumatology MDTs) often disease specific QoL measures relating to both specialties are used.<sup>17</sup>

Although, MDTs are well established across Europe, there is little published research concerning their effectiveness, though such evidence may emerge in the future.

### ***Patch Testing and establishing relevant allergens***



Significant improvement of HRQoL in subjects with contact dermatitis, eczema and hand eczema was reported after patch testing. Furthermore, patients with positive patch test results showed greater improvement in HRQoL compared with non-patch-tested patients and patients with negative patch tests results.<sup>26-29</sup> A review article on the impact of patch testing on QoL in allergic contact dermatitis also concluded that patch testing leads to QoL improvement.<sup>30</sup> Patch testing helps to diagnose the etiology of allergic contact dermatitis and hence provide targeted avoidance strategy and effective management. The mean DLQI score of subjects with latex allergy decreased from 17.9 to 10.9 after the diagnosis was established by testing.<sup>31</sup>

### ***Education***

When considering assessment of QoL of a patient with a chronic disease as an outcome measure, it is of paramount importance to initially adjust perception of the patient, so that their expectations are realistic. This can best be achieved through effective patient education, tailored for the individual. This is particularly important in skin diseases where there may be very little physical impairment but considerable psychosocial disturbance (e.g. disseminated psoriasis vulgaris or acne).

Educational intervention is a relatively new concept in dermatology. However, educational intervention has been attempted in a number of skin diseases focussing on different aspects of care including: disease information; treatment information; treatment regimens; adherence to treatment; skin care; counselling; self-management; use of an action plan; and medical corrective make-up. Most studies have demonstrated encouraging results and used HRQoL as a primary or secondary outcome measure.<sup>20,32-35</sup>

It is encouraging that there have been many well designed randomised controlled studies which provide evidence that tailored 'patient education' has a strong role to play in improving both clinical and QoL outcomes. Such evidence is more convincing where QoL is considered as a primary outcome measure and where patient education is compared with standard care alone or

as a plausible alternative.<sup>36</sup> Even familiar environment may improve efficacy of education sessions.<sup>37</sup>

To overcome the issue of the generalisability of the single centre studies described above, there is a need for examples of robust multicentre (multi-country) randomised controlled trials of alternative approaches to patient education and use of appropriate patient-reported outcome measures. A good example of such an approach is a multicentre randomised controlled study on moderate to severe AD involving 18 centres across Germany and one in Switzerland.<sup>38</sup>

As we seek to develop ways to support our patients in self-managing their skin disease, there should be greater emphasis on the development of validated educational interventions, evaluated using relevant clinical and patient-reported outcome measures. Further long-term studies are needed to provide evidence of the influence that educational programmes have on outcomes such as QoL and treatment adherence. In addition, the cost-effectiveness of novel educational programmes compared with standard care should be calculated. It is highly likely that patient educational programmes, developed with the involvement of patients and their family members, would lead to improvements in disease severity, QoL and tangible economic benefits. Such evidence may emerge in the future.

## **External services**

### ***Corrective make-up***

Appearance is important for the way identity is perceived and for self-esteem.<sup>39-41</sup> Skin conditions, especially affecting visible areas, such as face, neck, scalp, and hands, may harm people's emotional, social, and professional lives. Patients with debilitating skin disease may struggle with depression and even suicidal ideation.<sup>42</sup> Medical camouflage, by making skin conditions less visible, can have a positive effect on patients' HRQoL.<sup>39,41</sup>

Cosmetic camouflage refers to the use of opaque, cream, or wax-based cosmetic products applied to the skin to cover visible cutaneous disorders.<sup>41</sup> The application processes are different from the use of regular cosmetic foundations and so patients require training before using corrective make-up.<sup>43</sup> Such training in most cases has been provided by a specialized nurse or a trained cosmetician. A decrease in mean QoL scores (i.e. QoL improvement) after corrective makeup use was reported in all studies on vitiligo,<sup>34,39,40,44-47</sup> hyperpigmentation,<sup>39,45,46,48</sup> scleroderma,<sup>39-41</sup> lupus,<sup>39</sup> dermatomyositis,<sup>39</sup> sarcoidosis,<sup>39,46</sup> rosacea,<sup>39,40,45,46</sup> psoriasis,<sup>39,46</sup> scars,<sup>39,41,45,46,49</sup> acne,<sup>40,45,46,50</sup> discoid lupus,<sup>40</sup> capillary malformations,<sup>41</sup> café au lait macules,<sup>41</sup> ichthyosis,<sup>41</sup> congenital nevi,<sup>41</sup> hair loss,<sup>51</sup> skin adverse events due to chemotherapy,<sup>46</sup> angioma,<sup>46</sup> graft versus host disease,<sup>46</sup> tuberous sclerosis.<sup>46</sup> Positive effect on adult<sup>39,40,44-46,49-51</sup> and pediatric<sup>34,41,46,48</sup> patients HRQoL and family QoL<sup>41</sup> was reported. Patients with hair loss reported that topical concealers, hair-building fibers, hairpieces, and wigs improved appearance and self-esteem.<sup>49</sup> Medical camouflage can make a difference for patients with visible skin disease, reducing social anxiety and avoidance of social situations.<sup>52</sup>

### ***Climatotherapy and balneotherapy***

There are very few studies that have analysed the impact of climatotherapy on HRQoL of patients with skin disease. Climatotherapy at the Dead Sea for AD and vitiligo was investigated in two studies without control groups.<sup>53,54</sup> Significant HRQoL improvement in both studies was reported. The DLQI scores in women with vitiligo were higher than in men before and after the treatment.<sup>54</sup> Climatotherapy in the Canary Islands was investigated in AD and psoriasis patients.<sup>55,56</sup> The programme included sunbathing, individual consulting, psychosocial and physical stimulation in a relaxing atmosphere, education and swimming in the ocean. Both studies reported significant improvement in HRQoL. The factors most benefitted were improvement of the skin condition, followed by improved mood and increased ability to self-treat.<sup>55</sup>

A positive effect of the alpine climate on HRQoL of AD patients was reported in two studies.<sup>57,58</sup> One showed superiority of the treatment in a clinical setting in Davos, Switzerland compared to an outpatient setting in a moderate maritime climate in the Netherlands. However, at follow-up six months after intervention there was no difference in any of the primary outcome disease activities, including HRQoL.<sup>58</sup>

A positive effect of balneotherapy on HRQoL and family QoL of children with AD was reported. The treatment was well tolerated but mild, self-limiting, cutaneous discomfort such as erythema and a burning sensation occurred in 43% of patients.<sup>59</sup>

## **Psychological**

### ***Psychological intervention***

Emotional factors often influence the onset or the development of dermatologic diseases. It is therefore reasonable to consider that patients may benefit from nonpharmacologic treatments, aiming to help them to deal with the involvement of their emotions. There are several psychotherapeutic interventions ranging from counselling to psychotherapy. These involve working with patients to overcome their resistances and facilitating their openness to change, not only to get rid of the symptoms, but also to develop more positive attitudes. These approaches may encompass several techniques, including psychodynamic psychotherapy, humanistic therapies and family therapy. Cognitive behavioural therapy (CBT), hypnosis, biofeedback, psychoeducation and stress reduction techniques can be helpful to change some behaviours that are harmful to the skin.<sup>60,61</sup> In some patients, the psychiatric disorder is the primary disease and the skin condition is part of its expression, for example in neurotic excoriations, trichotillomania, factitious disorders or psychotic delusions. In psychosomatic patients, emotional factors, relationship factors and genetic and physical factors are working together in a complex system that influences the onset and the course of the disease.<sup>61</sup> The nature and location of the lesions

can impact on self-image and social interaction. Psychological techniques may help to control the intensity of itching and scratching in order to give the skin a chance to heal.<sup>60</sup>

### ***Psychological interventions: Cognitive therapy***

CBT is an empirically validated psychological intervention for a range of mental health disorders. The results for psoriatic patients with mild-to-moderate plaque psoriasis with psychological morbidity showed a significant improvement in mean DLQI scores compared with control patients.<sup>62</sup> The use of CBT in patients with AD resulted in a significant reduction of the mean DLQI scores.<sup>63</sup> Higher improvement of the emotional domain was found in psoriatic patients after one-to-one CBT stress-management sessions assisted with biofeedback compared to control group.<sup>64</sup> Greater improvement in quimp was achieved through mindfulness-based cognitive therapy course for patients with psoriasis compared to a control group.<sup>65</sup>

Habit reversal training (HRT), a multicomponent behavioural package to address repetitive behavioural habits, is a technique used for the control of scratching in AD. There was a significant reduction in eczema severity and improvement in HRQoL immediately following HRT.<sup>66</sup>

### ***Psychological interventions: Support groups and others***

However, a nursing care intervention programme “Coping with itch” in patients with chronic pruritic skin diseases resulted in only a small improvement of HRQoL after three months.<sup>67</sup> Joining a support group can also prove helpful in reducing disease severity and improving HRQoL. Significant improvement of HRQoL in children with AD after joining support groups was reported.<sup>68</sup> However, family QoL reported by their parents did not improve.

A video-assisted teaching programme on psoriasis and relaxation techniques led to significant improvement of HRQoL.<sup>69</sup>

Significant HRQoL improvement in adolescents with eczema and psoriasis after treatment in a Teenage and Young Adult (TYA) dermatology clinic with open-access psychological support demonstrated evidence that specialized adolescent care can improve outcomes.<sup>70</sup> A randomized controlled trial using a self-help intervention for psychological distress associated with skin conditions showed significant improvement in quimp.<sup>71</sup> A mindfulness-based stress reduction programme improved QoL in alopecia areata patients.<sup>72</sup> A study that examined the relationship between mindfulness and psychosocial distress highlighted the need for psychological support in patients with visible skin conditions and with low levels of mindfulness.<sup>73</sup>

### ***Psychological interventions: Hypnosis***

Hypnosis has been used since ancient times to assist in healing, and much early work on psychosomatic dermatology was based on hypnotic therapy. However, the absence of controlled studies makes it difficult to determine the true value of hypnosis. The most useful application appears to be in conditions where vasospasm or itching is a prominent symptom.<sup>60</sup>

Hypnosis has been used in patients with eczema, alopecia areata, hyperhidrosis, urticaria, rosacea, vitiligo and common warts, among others.<sup>74</sup> In medicine, hypnosis has been used to alleviate somatic symptoms, facilitate the healing process and reduce mental stress during medical treatment.<sup>75</sup> Hypnotherapy has been used in a number of skin diseases, but few studies have measured its impact on QoL.<sup>76,77</sup> Alopecia areata patients treated with hypnosis presented a statistically significant improvement in the SF-36 mental component summary score.<sup>76</sup>

## **Lifestyle**

### ***Lifestyle behavioral changes***

Lifestyle factors, such as diet, exercise, smoking, and alcohol may have an important impact on dermatological conditions. Changes of lifestyle habits are often suggested by clinicians to patients with chronic skin conditions in the hope of improving both clinical outcomes and QoL, as there is a relationship between modifiable life factors and dermatologic outcomes.<sup>78</sup> However, only a few studies have focused on the effect of life style modification on patients' QoL.

Several studies investigated the effect of weight loss in patients with psoriasis. Psoriasis and obesity share similar mediators of inflammation, mainly tumor necrosis factor- $\alpha$  (TNF- $\alpha$ ) and interleukin-6 (IL-6), thus, theoretically, weight reduction may result in clinical improvement. Moreover, some studies<sup>79-81</sup> have reported a QoL improvement in psoriasis patients on a low-energy diet compared to controls. In the follow-up study<sup>83</sup> of Jensen, 2013<sup>80</sup>, the decrease (improvement) in the DLQI score in the diet group largely persisted for 48 weeks. In another psoriasis study, a very low-calorie ketogenic, and then hypocaloric diet<sup>83</sup> resulted in a major improvement in the DLQI (median -13.4 points) at 10 weeks.

In hidradenitis suppurativa (HS) dietary modification to promote weight loss resulted in HS symptom reduction.<sup>84</sup> In a systematic review of dietary interventions in HS<sup>85</sup>, only one study mentioned impact on QoL.<sup>86</sup> Although no specific instrument was used to measure QoL, the authors of that study reported that there was a “return of [patients'] QoL and activities” after diet.

The effect of diet on QoL has been studied in patients with chronic spontaneous urticaria (CSU). Magerl<sup>87</sup> used the DLQI together with a clinical score to assess whether patients improved or not after a pseudoallergen-free diet. Also, a low-histamine diet has been shown to decrease symptoms and increase QoL in patients with CSU<sup>88</sup>, as measured by both the DLQI and the chronic urticaria QoL questionnaire (Cu-Q(2)oL). Oral food challenges in children with food allergy<sup>89</sup> are associated with significantly improved parent-reported QoL.

Beyond dietary intervention, other behavioural changes have been investigated. A review of lifestyle changes in psoriasis<sup>90</sup> included weight reduction, alcohol abstinence, smoking cessation, and exercise. The effect of an educational program for patients with psoriasis or AD, including changes in smoking behaviour and physical activity<sup>33</sup> resulted in a significant QoL improvement in the psoriasis group, but not in the AD group.

In chronic hand eczema a standardised care program including therapeutic patient education on hand care behaviours<sup>91</sup> improved clinical severity, QoL, and work productivity. Also an education program on hygiene and skin care regimen in lymphatic filariasis<sup>92</sup> improved patients' QoL.

It may be beneficial to patients with chronic skin conditions to take part in patient education programs aimed at modifying habits such as smoking and alcohol intake, and to consider promoting a low-fat diet and physical exercise. When assessing such interventions, it is important to evaluate the impact on patients' QoL as an outcome as well as clinical improvement.

### ***Religion and spirituality***

There are correlations between spiritual well-being and HRQoL of patients with cancer and cancer survivors as well as their caregivers.<sup>93</sup> Religion and spirituality could also offer those with skin diseases resources to help managing difficult situations.<sup>93</sup> The spirituality and inner peace experienced by some melanoma patients allowed them to value life, feel joy and strengthen relationships, improving their HRQoL.<sup>94</sup> Melanoma patients, compared to patients with other cancers, seem to have greater religious well-being (high faith scores) associated with social and functional well-being.<sup>95</sup> Malignant melanoma (MM) patients with strong religious faith reported less distress eight weeks after being screened for metastases than non-religious patients.<sup>96</sup> When managing patients with melanoma, their religious and spiritual needs should be



taken into consideration<sup>97</sup>, as their beliefs may interact with treatment decisions.<sup>93</sup> Caregivers, as well as stage III melanoma patients<sup>98</sup>, may also benefit from pastoral care<sup>97</sup> and religious belief.

Patients with various chronic diseases might benefit from a religious and spiritual dimension. In patients with systemic sclerosis (SS), lupus erythematosus (LE) and early stages of MM, evidence of spiritual well-being could predict low psychiatric burden.<sup>99</sup> Using the Multidimensional Inventory for Religious/Spiritual Well-Being (MI-RSWB), Pilch et al. showed a greater burden from the disease at the time of diagnosis for patients with LE, needing several years to accept the disease,<sup>100</sup> compared to patients with SS and MM. Compared with healthy persons, LE patients scored significantly lower for religious-spiritual well-being. For the same patients, joint pains and photosensitivity affected the ability to forgive.<sup>100</sup> Patients with MM reported higher transcendental hope.<sup>100</sup> On the other hand, patients with other chronic diseases such as psoriasis, rely little on religion as a coping strategy.<sup>101</sup> Psoriatic patients, as a whole, no matter how severe their disease, tend to use less active coping strategies, positive reinterpretation, humour or planning, compared to healthy controls.<sup>101</sup>

It seems that there is the potential, especially in patients with chronic and/or severe diseases, of accessing inner resources for coping and healing through the use of religious and spiritual help.

### ***Music***

Harmonic sounds, music and singing could improve our state of well-being.<sup>102,103</sup> Listening to Mozart's piano sonata K448<sup>104</sup> may improve spatial solving ability, and listening to pleasurable music may activate cortical and subcortical areas, where the emotions are processed.<sup>104</sup>

Vibroacoustic stimulation and exposure to relaxation music resulted in changes in skin conductance and improvements of patients' mood.<sup>105</sup>

Music may help patients cope with different health conditions<sup>103</sup> reducing the burden of the disease. Different types of music have different impacts, such as self-selected music inducing joy and classical music inducing relaxation,<sup>106</sup> suggesting specific music for different conditions. For example, in AD, listening to Mozart improved skin whealing induced by latex (but not by histamine), reduced production of total IgE, latex-specific IgE and Th2 cytokines, and increased production of Th1 cytokines. Beethoven's music did not have the same effect.<sup>107</sup>

Pruritus has a major impact in many skin diseases. High intensity and duration of itch can provoke and maintain stress and influence mood and QoL. The groups of psoriasis and AD patients with music therapy had reduced blood pressure and pulse rate, a marked decrease in the desire to scratch and a reduction in the level of disease activity. The music impact was more pronounced in the psoriasis group. Music may be useful as an adjuvant to other therapies.<sup>108</sup>

In a randomized case-control study of pruritus in patients with psoriasis, AD and contact eczema, pruritus had a significant impact on HRQoL. The music group experienced a significant reduction of pruritus intensity compared to the emollient group. In the music intervention group, 64% of patients reported improvement and intended to continue music therapy.<sup>109</sup>

In a controlled experiment to assess the impact of live saxophone music on patients undergoing haemodialysis, a range of parameters were recorded, including pruritus and impact on QoL. In the music group, pruritus was reduced by 76% with improved QoL.<sup>110</sup>

Chronic vascular ulcers are often painful and require lengthy sessions of dressing of the wound. A pilot study with adjunctive aromatherapy (lavander and lemon) or music therapy, with controls during wound dressing change showed significant improvement of pain intensity in the patients with lavander and those who listened to relaxing music. These simple complementary therapies used along with dressing changes could comfort and might have an analgesic effect, leading to improved HRQoL.<sup>111</sup>

One live music therapy session directly after wound care in children with burns showed a reduction of self-reported distress in children older than five years, but not for the younger ones.<sup>112</sup>

Relaxing recorded music or live music could reduce the discomfort and could improve patients attitudes towards dermatological procedures or surgery.<sup>113</sup> Personalized music could be used to reduce perioperative anxiety in Mohs surgery for skin cancer.<sup>114</sup> However, single-blinded randomized controlled trials on dermatological surgical procedures using relaxing music apparently did not demonstrate reduction in patient pain or anxiety during excisions under local anesthetic, whereas the relaxing music had a positive effect in decreasing the surgeon's anxiety.<sup>115</sup>

There are also suggestions that soothing music could reduce stress, blood pressure and also post-operative trauma, when compared to silence.<sup>116</sup>

Music could be a pleasant, inexpensive adjuvant as background ambiance during examinations, interventions, before and after dermatologic surgery and also together with specific therapy in reducing itch and pain, improving anxiety and HRQoL.

## **Conclusions**

The way that skin diseases impact patients may differ widely. There is a wide range of aspects of a person's life that may be affected and these aspects may be more or less impacted depending on a variety of factors, including disease type, age, gender, and local cultural factors.<sup>117-127</sup>

Therefore approaches to understanding and assisting patients need to be individualised to be maximally beneficial. There may be many other individual ways in which a caring holistic health care professional may contribute to the improvement of a patient's QoL. Our literature review did not reveal the general "common sense" and other appropriate actions that may be second nature to many dermatologists. These include, for example, indicating by patient approach and physical contact that there should be no stigma attached to skin disease and that there may be

ways to cope with any such perception. There may also be public health interventions to improve the QoL of people with skin disease, for example the promotion of supportive attitudes to ensure that people with psoriasis may freely use public swimming baths.

Psychodermatology is a subspecialty that includes psychological and non-medical interventions in the dermatological consultation or in a MDT. Psychodermatology training includes the knowledge of those various tools that the dermatologist can use in daily practice, and adapt to the patient. Education, negotiation of the best possible treatment depending on the patient's context and motivational intervention should be part of every consultation for chronic skin conditions.

It is important for clinicians to routinely consider the use of methods to improve the QoL of patients, beyond medicines. However this may be particularly relevant in situations when use of some therapeutic approaches are limited: for example during pregnancy or lactation, while immunosuppressed or during the COVID19 pandemic.<sup>128,129</sup> There are other challenging situations where special attention should be paid to the possible benefits of non-drug approaches, such as where a patient is very ignorant about their skin disease,<sup>130</sup> where there is poor compliance or adherence to treatment,<sup>131</sup> if there are unmet needs<sup>132</sup> or if the patient or carer has some degree of corticosteroid phobia.<sup>133</sup> Of course there are many difficult to treat skin conditions such as severe forms of epidermolysis bullosa and other genodermatoses, where supportive therapeutic approaches are particularly important. More detailed information on methods of QoL assessment in dermatology has been presented in previous publications of our TF.<sup>134-143</sup>

The ultimate aim of therapy is to eradicate a disease in an individual and return the person's life to normal. However, until the day comes when this has been achieved for every skin disease and for every patient (presumably not in the lifetime of any current reader), there will be a need to support and assist many patients using additional non-pharmaceutical ways (see Figure 1). These "adjuvant" approaches receive too little attention while dermatologists and researchers strive for

better pharmacological therapies. The different ways in which patients may benefit have been reviewed here, but the reality is that for most the evidence is very poor and further investigation is required. The research challenges that we have to meet are to identify those approaches that might be of value and to provide further evidence for their optimal use. In the meantime, clinicians should consider the use of these approaches where QoL remains impaired despite optimal use of the available standard therapies.

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Table 1. Non drug interventions that may improve quality of life

Figure 1. When to consider non-pharmaceutical interventions