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Skin Disorders and Quality of Life

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Introduction

Chronic skin disorders like psoriasis and atopic eczema have profound influence on patients' lives. More or less visible painful or itching symptoms affect patients' social life, their daily work and their personal relationships. Nevertheless, very often the influence of chronic skin diseases on the Quality of Life (QoL) might be underestimated in comparison with other more life threatening disorders like cancer or heart disease. Comparing health-related QoL of 317 patients with psoriasis and QoL of patients with 10 other diseases, Rapp et al. (1999) found that in patients with psoriasis the impaired physical and mental functioning was comparable to that seen in cancer, arthritis, hypertension, heart disease, diabetes, and depression. Chronic skin diseases do not only affect patients QoL, but also have impact on the patient's family or their partner. Basra and Finlay propose the concept of the "Greater Patient" to describe the immediate close social group affected by the patient. They recommend seeing the patient as "the centre of a complex web of surrounding relationships", which makes it important to keep also in mind the QoL of the family and their partners (Basra and Finlay 2007).

Looking at the QoL of children with different chronic diseases noted that children with cerebral palsy showed the greatest impairment of QoL, followed by atopic dermatitis, renal diseases and cystic fibrosis. The QoL of children with psoriasis was more reduced than that of children with enuresis, diabetes and epilepsy (Beattie and Lewis-Jones 2006a). Beside problems in daily life and personal relationships the feelings of stigmatization, increased anxiety, depressive symptoms and following avoidance of social activities are very common in chronic skin disorders and should be kept in mind in the treatment of those patients. This article will focus on the frequent chronic skin disorders psoriasis and atopic eczema and their influence on QoL. Because stigmatisation is one of the most important psychological aspects of skin diseases it is highlighted in this article. The increasing acceptance of recognizing the value of QoL studies in psoriasis and atopic dermatitis treatment research supports the opinion that the somatopsychic view is the most important psychodermatological aspect. However, some recent psychoneuroimmunological studies suggest new psychosomatic connections in psoriasis and atopic dermatitis going beyond questions of conflict or personality specificity (e.g., Kiecolt-Glaser et al. 2002, Stephan et al. 2004, Buske-Kirschbaum et al. 2007, Schmid-Ott et al. 2009).

Defining Quality of Life (QoL) and Feelings of Stigmatization

In the last decades measuring of QoL in different diseases became more and more important in medical research. Beside physical well-being QoL contains also social, mental and emotional well-being and might be influenced not only by the specific disease, but also by different concomitant factors. Knowledge about the impact of disorders on the QoL becomes more and more important in the sense of a more holistic understanding of diseases. This may lead to more effective therapies. Keeping patient's QoL in mind may also have an influence on the decision of treatment in the clinical routine and consecutive on patient's compliance. The impact of disease-related QoL might be best estimated by the patients themselves. Multiple validated measuring instruments exist for medical research. Special measuring instruments have been configured for skin disorders. Only three of them should be mentioned briefly, because of their frequent use in dermatological studies. The Dermatology Life Quality Index (DLQI) by Finlay and Khan (Finlay and Khan 1994, Basra et al. 2008) is a health quality of life scale comprised of 10 items which focus on 6 dimensions: 'symptoms', 'daily activities', 'leisure', 'work', 'personal relationships' and 'treatment'. For estimating children's QoL, the Children's Dermatology Life Quality Index (CDLQI) - which is very similar to the DLQI - has been developed (Finlay and Khan 1994). The Psoriasis Disability Index (PDI) measures the impact of psoriasis on specific aspects of daily living consisting of 15 disease-specific items (Lewis-Jones and Finlay 1995, Finlay et al. 1990).

Skin diseases very often come along with symptoms which may be very discriminating. Patients with visible skin symptoms are often glared at or even avoided for fear of infection or for disgust. So, in speaking about the QoL of skin disorders the experience of stigmatization is an important factor which should not be neglected. Stigmatization - defined as a process in which skin appearance is negatively judged and persons who are affected experience absence of acceptance because of their visible symptoms - may have profound consequences in the life of patients, such as increased anxiety or social avoidance.

Quality of Life in Different Skin Diseases

Atopic dermatitis

Atopic dermatitis (AD) is a chronic inflammatory skin disorder that presents itself often during early childhood and may persist in adulthood. Sometimes it even starts in adulthood. Over the last decades the prevalence has increased continuously up to a lifetime prevalence in children of 10-20% and 1-3% in adults (Leung and Bieber 2003). It is well known that AD has great impact on the Quality of Life (QoL) of patients and their families. There are several studies demonstrating this matter of fact. Comparing children with AD or other chronic diseases it has been found that AD has a greater impact on the QoL of children than for example diseases like epilepsy and diabetes (Beattie and Lewis-Jones 2006a).

Itching and scratching, as well as difficulties with falling asleep and problems with bathing, show very great impact on the QoL in affected children. However, in the

parents' emotional distress, sleep loss and tiredness/exhaustion are important influencing variables (Beattie and Lewis-Jones 2006a). Quality of life and disease severity in children may be correlated (Ben-Gashir et al. 2004). Atopic dermatitis may not only influence childhood but also the further life of those who are affected. Brenninkmeijer et al. (2009) found out that children with severe atopic dermatitis showed a significant delayed social development in their further course of life. Looking at adults with AD, higher anxiety levels could be found in comparison to a healthy control group (Linnet and Jemec 1999). A beautiful skin has great influence of the sexual attractiveness of a person, so it can be assumed that AD may even have impact on the sexual life of the patients and their partners. Misery et al. (2007) showed that 57.5% of patients with AD noted a decreased sexual desire and 36.7% of their partners reported that the appearance of eczema had an impact on their sexual life. A German study showed that the exchange of tenderness in patients with AD and psoriasis was significantly reduced. Although this issue may be very discriminating for the individual, 96% of the patients with AD indicate that their attending physician have never addressed that problem (Niemeier et al. 1997).

Psoriasis

Psoriasis is a chronic skin disease affecting even joints with a prevalence between 0.5% and 4.6% (Lebwohl 2003). Different studies suggest that psoriasis is associated with an increased cardiovascular risk and a higher prevalence of metabolic syndrome (Gisondi et al. 2007, Neimann et al. 2006). It is well known that psoriasis may affect the whole life of patients. The results of a National Psoriasis foundation patient-membership survey, which has been performed in the United States in 1998, showed that 79% of the patients with psoriasis felt impaired by their disease. It was noticed that elderly patients felt less impaired by the psychosocial consequences than younger people between 14 and 54 years. Young patients between 18 and 34 years especially stated a very high psychological burden in comparison with other ages (Krueger et al. 2001). Similar results have been found in a European study investigating patients with psoriasis in the Nordic countries. Married and older patients showed less impairment of QoL than younger patients and those living alone. The most important predictive factor of psoriasis-related QoL in this study was self-reported disease severity (Zachariae et al. 2002). Additionally, Sampogna et al. (2007) found that especially in elderly women with co-morbidity of depression and anxiety the influence of psoriasis on the QoL is very high.

A further large European study with 17,990 psoriasis patients investigating their disease-related QoL showed a high percentage of patients (77%) pointing out that they have problems or significant problems with their disease (Dubertret et al. 2006). Looking at the 3753 German participants of this study, 47% of them referred 'clothing', 44% 'more frequent bathing than normal' as a special problem, and 35% felt impaired in their sporting activities. 'Going to the hairdresser' causes problems for 29% of the participants and 'going to a public bath' is a problem for 21% of them. And last but not least, 23% of participants told of adverse affects of the psoriasis on their sexual life (Schmid-Ott et al. 2005b). Understandably, psoriasis affects also the lives of partners and family members concerning many different aspects of everyday life. In questioning 63 relatives and partners respectively of 33 patients with psoriasis, Eghlileb et al. (2007) found that only 8% of all did not notice any influence of their lives.

Co-morbidity of psychiatric disorders is common in dermatologic disorders. Approximately 30% of all dermatologic patients show psychiatric disturbances (Gupta and Gupta 1996), whereas major depressive disorders are the most frequent. A study screening 265 patients with psoriasis for depressive symptoms revealed a rate of 32% of patients with a positive screening for depression (Schmitt and Ford 2007). As it is known, depressive symptoms are often associated with suicidal tendency. So it is not surprising to find a prevalence of active suicidal tendency among psoriasis inpatients of 7.2%, which is higher than the 2.4 – 3.3% prevalence reported among general medical patients (Gupta and Gupta 1998). A similar prevalence of 10% of suicidal thoughts in patients with psoriasis has been found by Picardi et al. (2006). These findings show the need to take care of psychiatric co-morbidity in patients with psoriasis.

Vitiligo

Basra and Shahrukh (2009) report on the burden of vitiligo that approximately 75% of those concerned estimate their appearance as moderately to severely intolerable (Salzer and Schallreuter 1995). In addition some of them have low self-esteem, fear, anxiety, stress and a feeling of shame in social interactions (Van Moffaert 1992, Porter et al. 1979, Porter et al. 1986, Ahmed et al. 2007). Female vitiligo patients show a more impaired QoL than men, which can be compared with the impairment experienced by psoriasis patients (Ongenae et al. 2005).

Skin Cancer

Cutaneous malignant melanoma (MM) is less common than the basal cell and squamous cell carcinomas; however, it has a much higher mortality. The most important contribution of the psychosomatic medicine in the treatment of MM patients is supporting their coping which is central for the QoL of the concerned (cf. Söllner et al. 1998). The review of Basra and Shahrukh (2009) summarizes the studies concerning QoL of skin cancer patients: patients with recent diagnosis of MM experience the same levels of psychic distress as other cancer patients (Fawzy et al. 1990). At 3 months after surgical intervention, around 20 % of MM patients showed clinically high levels of anxiety; however, depressive symptoms seem more often in patients with metastatic melanoma (Brandberg et al. 1992b). Women with the disease have higher levels of anxiety and depression (Brandberg et al. 1992a).

Squamous cell and basal cell carcinomas (i.e. nonmelanoma skin cancers [NMSCs]) of the skin are the most frequent malignant tumors in the Caucasian population (Joseph et al. 2001). The incidence of this kind of carcinomas increases and is 18-20-times greater than MM (Diepgen and Mahler 2002). The location of NMSCs on visible areas, i.e. face, head or neck, suggests a higher probability of psychic or social consequences. In addition, most of the present treatments result in scars (cf. Bock 2006) mostly on visible areas and partly with a relevant disfigurement.

Urticaria

The review of Basra and Shahrukh (2009) summarizes that urticaria may have a relevant impact upon the QoL of the concerned. Increased anxiety and depression have been

observed in patients with chronic urticaria as well as restriction of clothing and footwear choices, mainly due to the pressure effect of tight-fitting wears aggravating the symptoms (Basra and Shahrukh 2009). Because exercise has been suggested to provoke urticaria in some of the concerned, many patients avoid exercise. In addition, affection of social life, mobility, sleep, and sexual relationships have been reported (O'Donnell et al. 1997).

Feelings of Stigmatization in Different Skin Diseases

Negative impact of psoriasis and AD on QoL can be influenced by feelings of stigmatization. Very often patients with psoriasis and AD experience rejection because of their visible symptoms. Strangers or even friends and relatives may show disgust or fear of infection. Social reclusiveness associated with anxiety, depressive symptoms or even alcoholism or other addictions can be the consequences. Patients may even feel disgust of their own body and suffer from a low self-confidence. And in a vicious circle these feelings may lead to an impairment of the skin disease and further stigmatization.

Schmid-Ott et al. (2003) investigated 463 patients with psoriasis and atopic eczema for their experience of stigmatization and the influence on QoL. Correlations have been found between stigmatization and QoL in terms of a negative influence of stigmatization on the QoL. Comparing patients with psoriasis with those who have an atopic dermatitis no significant differences could be found concerning their experience of stigmatization and their self-reported QoL. In contrast, Vardy et al. (2002) found in comparing psoriasis with other chronic skin disorders (acne vulgaris, atopic dermatitis, viral and fungal infection, sun-damaged skin and different types of eczema) patients with psoriasis suffer more from experiences of stigmatization than a control group consisting of patients with mixed different other dermatologic diseases . A study with 125 patients with atopic dermatitis revealed similar results. Perceptions of stigma were significantly associated with quality of life and an association was found between perceived stigma and disease severity (Wittkowski et al 2004). But even if the severity of psoriasis is not very distinct, lesions on invisible parts of the body can already cause serious adverse impairment (Schmid-Ott et al. 2007b).

Vitiligo

Schmid-Ott et al. (2007a) examined the extent of stigmatization experienced by 363 vitiligo patients considering the visibility of the lesions. The patients were assessed using the Experience with Skin Complaints (QES), Adjustment to Chronic Skin Disorders (ASC), and Sense of Coherence (SOC) questionnaires. Out of the total patients group two representative samples with 52 patients each were identified with comparable characteristics of age, gender, and duration of the skin disease; the first with visible and the second with invisible lesions. Data indicate a significant negative correlation between the QES dimensions, except for 'Composure', and between coping scales with sense of coherence withstanding. The 'visible lesions' group scored higher compared to the 'invisible lesions' group on the two QES scales 'Self-Esteem' and 'Refusal', i.e., patients with visible lesions experienced a higher level of stigmatization.

Strategies to Improve Quality of Life and Reduce Stigmatization in Skin Disorders

Today we know good therapies do not only focus on the organic symptoms of a disease, but are aimed also at the improvement of QoL and the prevention of secondary psychiatric diseases like depression or anxiety caused by the chronicity of the disorder. Especially in chronic diseases, coping with the disease is very important as a motivational factor for undergoing long and restrictive therapies.

Medical research allows for these aspects and a lot of studies not only investigate the medical effects of different therapies but also their consequences on the QoL of the patients (Kawashima and Harada 2007, Drake et al. 2001, Van de Kerkhof 2004). Surely, a phase adapted dermatological therapy of chronic skin disorders like psoriasis and AD is indispensable. Certainly, healing of visible and distracting skin symptoms lead to an improvement of QoL. But beside essential dermatologic therapies, further supporting measures may be helpful. Very often dermatologic therapies take a lot of time and frequently, success may be only seen with delay. Unfortunately, relapses occur regularly and may have negative impact on the motivation for therapy. A good physician-patient relationship can be very helpful in preventing this problem. The attending physician should not only be able to prescribe the right medication, but also to motivate his patient in phases of insufficient success. He should although take time to speak with his patient about the consequences of the skin disorder on his daily life.

Symptoms of anxiety and depression should be addressed in evaluating if further psychotherapeutic measures should be considered. Different psychological approaches are available and for some of them supporting effects could be demonstrated. A meta-analysis of the effects of eight different psychological interventions (aromatherapy, autogenic training, brief dynamic psychotherapy, cognitive-behavioural therapy, dermatological education, habit reversal behavioural therapy, a stress management program, and structured educational programs) on atopic dermatitis achieved by Chida et al. in 2007 revealed significant ameliorating effects on eczema severity, itching intensity and scratching, but a definite conclusion about the effectiveness of those therapies could not be drawn.

Recently, Idriss et al. (2009) examined the role of online support communities for patients with psoriasis and his study revealed, that the intensity of participation in online support was associated with improved quality of life. Psoriasis virtual communities are found to be a valuable educational resource and a source of psychological and social support. Finally, a 1-year follow-up of the illness and its psychosocial consequences in psoriatic men and women showed a moderate but significant relevance of skin state for feeling of stigmatization over time only in men, thus suggesting a considerable influence of other psychic variables, probably coping skills, especially in women (Schmid-Ott et al. 2005a).

Patient associations like the National Psoriasis Foundation in the U.S.A. or the German Psoriasis Association offer the possibility of getting information about the disease and are a platform to get in contact with other attended patients. Not every patient with psoriasis

or atopic dermatitis needs a specific psychotherapy, but if a patient prefers to cope actively with his disease, educational outpatient programs might be a good opportunity. Good results are available especially with parents of young children with atopic dermatitis. In an Italian program improving knowledge of the disease produced lower anxiety levels in parents (Ricci et al. 2009). A German multicentre, randomised controlled trial of age related, structured educational programs for the management of atopic dermatitis in children and adolescents revealed significant improvements in severity of eczema and subjective severity in all intervention groups after the program. Even the QoL of the parents was improved after undergoing those educational programs (Staab et al. 2006).

Conclusion

Chronic skin disorders like psoriasis and atopic eczema have profound influence on the patient's QoL. Patient's daily life and their relationships can be significantly impaired and social avoidance, depressive symptoms and anxiety might be negative consequences. A very important factor, especially in skin disorders, is experience of stigmatization due to visible and even hidden skin lesions, which are only relevant in personal relationships. More and more, medical studies focus on these problems and therapies should not only treat the skin lesions, but should be aimed on an improvement of QoL.

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