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HOT CLINICAL STUDY

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Quality of life of patients with keloid and hypertrophic scarring

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Abstract Keloid and hypertrophic scarring represent chronic disfiguring dermatoses with a high resistance to therapy. The aim of our study was to assess for the first time the quality of life of patients with hypertrophic scars and keloids, because they suffer from quality of life impairment as much as patients with other chronic skin diseases. An item-pool was created modifying and supplementing the items of the Questionnaire on Experience with Skin Complaints. This questionnaire was distributed to 100 outpatients with keloids and hypertrophic scars. A factor analysis was used to identify the underlying dimensions. Two scales (psychological and physical impairment) of the questionnaire with nine and five items, respectively, were established. Test–retest reliability of the questionnaire was excellent (corr > 0.9). Good validity was suggested by the correlation of physical impairment with pain ($P \leq 0.001$), pruritus ($P < 0.001$), and the amount of restriction of mobility ($P < 0.001$). The psychological scale was associated with pain and restriction of mobility, although the correlations were lower. This study demonstrates for the first time an impairment of quality of life in a large group of patients with keloid and hypertrophic scarring.

Keywords Quality of life · Keloid · Hypertrophic scarring

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Introduction

Keloids and hypertrophic scars are the result of pathological wound healing in genetically predisposed individuals [5, 21]. It is not well documented how commonly keloids occur in the general population. The reported incidence range from a high of 16% among adults in Zaire to a low of less than 1% among adults in England [10]. It is widely accepted that dark-skinned populations have a higher occurrence of keloids than light-skinned populations, but the reported incidence ratio between the two groups ranges from 2:1 to 19:1 [1].

Although the pathogenesis of these conditions is still unknown, dysregulation of transforming growth factor ß (TGFß) as well as of other factors involved in the complex regulation of wound healing has been demonstrated [30]. However, gene polymorphisms for TGFß have not been detected in keloid patients [3, 4, 6].

Keloids and hypertrophic scars occur predominantly in areas of high skin tension and on the chest wall. In many affected patients lesions are found in regions of the body which are difficult to hide. There is a steady increase in incidence of keloids in anatomical regions for decoration piercings such as earlobes particularly in dark-skinned children which becomes an increasing medical problem [18]. In younger age groups and female patients, keloids are found more often in multiple anatomical sites [2]. Furthermore, keloids and hypertrophic scars tend to itch and hurt and may also restrict mobility [9, 19]. Therefore, these conditions have a direct and indirect effect on the quality of life.

Numerous investigations have been performed to assess the quality of life of patients with chronic skin diseases like psoriasis and atopic dermatitis [11, 25, 26, 32, 33]. Skin lesions of chronic skin diseases relevant to psychosocial interactions may induce stigmatization. To experience feelings of stigmatization may produce mental stress and correlate negatively with the quality of life. The major impact on the quality of life of dermatological disorders such as psoriasis in comparison with other

non-dermatological conditions has been shown previously; it was demonstrated that the quality of life of psoriasis patients is as much reduced as of patients with severe heart failure or diabetes mellitus [24].

Quality-of-life investigations are rare in patients with pathological scarring. As an exception, a number of studies have been performed in patients with burn injuries and subsequent scarring [8, 28, 34]. However, in keloid and hypertrophic scarring, there is still no prospective analysis using validated instruments in a large cohort of patients. Furthermore, keloids and hypertrophic scars are not often properly discriminated from various clinical phenotypes of normal scarring.

Clinical experience suggests that patients with keloid and hypertrophic scarring suffer as much as patients with other chronic skin diseases and that this impairment in the quality of life is influenced mostly by internalized and experienced stigmatization. The recognition of stigmatization plays a central role in patients with skin diseases and is often more important to the patient than the physical disease [12, 13]; for example, by mediating the impact of disease severity on quality of life in vitiligo or psoriasis [14, 15, 17, 31]. Having a stigma and being excluded from full social acceptance is a central problem for all persons who are "different" as compared to "normal" [14]. This background underlines the need for a questionnaire that is able to determine this stigmatization experience and quality of life in patients with keloid and hypertrophic scarring. Beside the clinical manifestation, psychological measures, especially quality of life are very important parameters in determining the efficacy and acceptance of disease treatments [16].

Therefore, the development of specific questionnaires designed to measure quality of life in a given disease is highly desirable.

The aim of the study presented was to analyze the quality of life in patients with keloids and hypertrophic scars and to show that the results are comparable to investigations in other skin diseases. For this purpose, a new questionnaire was developed in order to measure relevant dimensions (validity) in a reliable fashion (reliability).

The main hypothesis of this study was that psychological and somatic symptoms of pathological scarring could be represented by the different dimensions of the questionnaire. In addition, the assumption was made that these dimensions are psychometrically sufficient.

Methods

The development of the questionnaire began with the selection of items with regard to the physical and psychological problems associated with this disorder. An item pool was formed by screening the items of the questionnaire on Experience with Skin Complaints [25, 26] concerning their relevance for patients with scars. In a second step, these items were semantically modified. After this, a pilot study was conducted on ten outpatients presenting the selected items in a preliminary questionnaire. This pilot study resulted in a sufficient comprehensibility and acceptability of these items.

Items were graded in six steps (−5 = totally inaccurate, −3 = inaccurate, −1 = somewhat inaccurate, 1 = fairly accurate, 3 = accurate, 5 = completely accurate). This scaling was preferred to make sure that there is the same distance (−2 and 2) between each step ("requirement of equidistance").

The study population is a result of consecutive examination of outpatients seen in a scar-service at the Department of Dermatology, University of Kiel, over a period of 11 months. In order to determine reliability, this questionnaire was handed out at the first examination and 2 weeks later (2-week test–retest method).

Since there are distinct morphological as well as pathogenetic differences between keloid and hypertrohic scarring as compared to normal scarring [1], patients with keloids and hypertrophic scars were clinically identified by trained dermatologists (O. Bock, U. Mrowietz).

Lesions of the patients were classified as keloids or hypertrophic scars and discriminated from normal scars using a specialized proforma differentiating the number of scars and the regions of the body affected, for example, visible (head, lower arms or lower legs) and nonvisible sites. Thus, first results regarding validity could be obtained by comparison with clinical findings. In addition, single items measured subjective intensity of and suffering from disease (graded as six steps from very slight/none to very severe). Different aspects clinically characterizing the disease (pruritus, intensity of scar pain, decrease of mobility) were measured on an analogue scale from 0 to 10. Finally, basic sociodemographic data were gathered.

Then a factor analysis (maximum-likelihood procedure, varimax rotation) of 34 items was performed to analyse the underlying latent constructs of this item pool. The scree-criterion could not be interpreted definitely, suggesting use of a two- or three-factor solution. However, two dimensions of the three-factor solution representing different aspects of the psychological impairment induced by keloid and hypertrophic scarring, that is, intrapsychic point of view and interpersonal relationships, showed high correlation. Therefore, the two-factor solution was chosen corresponding to a distinct content of each factor ("psychological impairment" and "physical impairment").

A binomial test was performed to determine the deviation of the sex relation in this sample from the expected relation ("true prevalence"). Relations between the two scales of this questionnaire to relevant sociodemographic (e.g., age, gender), disease related (e.g., duration, pruritus, pain, restriction of mobility due to disease) and psychosocial parameters (e.g., visibility, suffering from disease) were determined by the "Pearson-correlation." The data were analyzed using the statistics program system SPSS.

Results

Description of the study population

The study included 100 outpatients (66 women) with keloid and hypertrophic scarring at the Department of Dermatology, University of Kiel, Germany. Mean age was 36.1 years (range: 10–80 years, SD = 17.2).

Hundred completely answered questionnaires were received (90.1% of the distributed questionnaires) after 14 days (range = 6–24 days, mean = 14 days, SD = 3.6).

Further characteristics of the sample are shown in Table 1. Compared to the estimated prevalence regarding gender (1:1), our sample showed a lower number of male patients (34%, binomial test: $P = 0.0018$, zero-hypothesis = 50% female, 95% confidence interval of this parameter: 25–44%).

Table 2 shows the localization of keloids and hypertrophic scars. Because the patient might have several scar locations, the percent does not sum to 100%. The highest incidence of pathological scarring was found on the ventral side of the trunk (presternal area, 75%). The anogenital area showed the lowest incidence of pathological scars.

Creation of the scales

Table 3 shows the results of the factor analysis. Only items which are used for the scales are displayed in this table. Item 28 "I have thought of committing suicide because of my scars" was also included because of clinical interest, even though it does not definitely belong to one of the two scales.

A two-factor solution ("psychological impairment" with nine items and "physical impairment" with five items) was chosen, due to ambiguous results of the scree-criterion which suggested a two- or three-factor solution.

Table 1 Overview of the study population

Gender	66 females, 34 males
Age (years)	Min = 10, mean = 36.1, median = 32.0, max = 80, SD = 17.2
Duration of disease (years)	Min = 0.4, mean = 7.2, median = 5.3, max = 33.4, SD = 5.8

Table 2 Localization of keloids and hypertrophic scars ($n = 100$)

(%)	Ventral	Dorsal	Ventral and dorsal
Head	15	1	0
Trunk	75	40	26
Upper arms	8	1	1
Lower arms	18	4	3
Leg below knee	8	3	0
Leg above knee	9	3	2
Anogenital	6	1	1

Table 3 Results of the factor analysis of the total sample ($n = 100$): The two scales (factor 1: psychological impairment and factor 2: physical impairment) of the questionnaire

	Factor 1	Factor 2
1. Changes in the weather seriously affect my scars (pain, feeling of tension)	0.1	0.56
2. My scars restrict my mobility	0.06	0.63
3. I succeed in disregarding the reservations others have concerning my scars	−0.52	−0.1
4. The itching in my scars frequently affects me	0.02	0.76
5. Due to my scars I am sometimes too ashamed to be sexually active	0.64	0.04
6. I find it difficult to put up with the itching caused by my scars	0.12	0.7
7. I do my best to prevent even people close to me from knowing that I have scars	0.73	0.12
8. I cannot prevent myself from scratching when my scars itch	0.08	0.57
9. I feel physically unattractive and sexually undesirable when I think about my scars	0.71	0.19
10. I find it difficult to accept my scars	0.81	0.08
11. I don't visit the swimming pool or the sauna since other people could feel disgusted because of my scars	0.65	0.06
12. I never feel embarrassed or ashamed because of my scars	−0.58	0.14
13. One has less self-confidence with scars like I have	0.6	0.24
14. I feel uncomfortable when asked questions about my scars	0.69	0.22
15. I have thought of committing suicide because of my scars	0.32	0.08

However, two dimensions of this three-factor solution described antipodal aspects of the psychological impairment induced by keloid and hypertrophic scarring, that is, the intrapsychic point of view and interpersonal relationships. In addition, these two factors showed a high correlation and were, therefore, merged. Item 28 (15 in Table 3) did not load on to any factor. Further studies will have to verify if item 28 which focused on committing suicide because of the scars belongs to the first or to the second scale.

Both scales were calculated as the mean of the items. Thus the mean scale value of the two dimensions can be assigned to the semantic anchors of the Likert Scale. The items of the first scale (psychological impairment; item 3, 5, 7, 9–14) describe feelings of worthlessness, the experience with a lack of physical attractiveness or sexual desirability in the context of the scars and special ways of avoiding public situations. The second scale (physical impairment) consists of the items 1, 2, 4, 6, and 8. It is characterized by physical aspects like "Changes in the weather seriously affect my scars (pain, feeling of tension)" or "My scars restrict my mobility"; this scale also deals with itching and scratching in the context of scars. These two factors explained 19 and 11% of the total variance of all factors.

Test–retest reliability

Table 4 shows test−−retest reliability (between the first and second measure) and Cronbachs alpha. Both scales proved to be independent of each other. Reliability was high. The test−−retest reliability in scale 1 was 0.96 and 0.94 in scale 2. The correlations between both the scales were low, both at the first measure (0.21 and 0.22) and between the measures (scale 1 at the first measure and scale 2 at the second measure: 0.22 and vice versa: 0.20). A second analysis with the concordance correlation coefficient, which is suggested to be a better measure of the test−−retest agreement [20], revealed comparable results. The difference between both the correlations corresponds to the fact that the concordance correlation coefficient considers the parameter value of the measure.

Correlation of the scales to other physical and psychological parameters

Table 5 shows relations between scales 1 and 2 and other single items which clinically characterize the disease. A correlation of 0.25 and 0.24 was found between scales 1 and 2 and the intensity of disease. Scale 1 showed a high correlation to "Suffering from disease" (corr. 0.64). Scale 2 showed a high correlation to "Restriction of mobility due to disease" (corr. 0.51). In contrast, no correlation to age, gender, and duration of disease was found except a moderate correlation of scale 2 and age (corr. 0.25). Visible keloids or hypertrophic scars on the head, lower arms, or lower legs had a strong influence on scale 1 "psychological impairment."

Table 4 Cronbach's alpha, test-retest reliability estimated through the Pearson-correlation (R) coefficient ($n = 100$)

	Test scale 1	Test scale 2	Retest scale 1	Retest scale 2
Cronbachs alpha	0.88	0.78	0.86	0.77
Test scale 1	1	–	–	–
Test scale 2	$R = 0.21$	1	–	–
Retest scale 1	$R = 0.96$	$R = 0.2$	1	–
Retest scale 2	$R = 0.22$	$R = 0.94$	$R = 0.22$	1

Discussion

This is the first study describing a new questionnaire to investigate and measure the quality of life of patients with keloid and hypertrophic scarring. This new questionnaire was distributed to a large number of outpatients ($n = 100$) at the Department of Dermatology, University of Kiel, Germany.

Keloids and hypertrophic scars are well-known dermatologic conditions which occur after surgery, trauma, or may also develop spontaneously. Lesions may be single or disseminated—like in acne patients. They can restrict mobility when present over joints. Many patients report itch, pain, and discomfort. Treatment of keloids and hypertrophic scars is difficult, often painful, long-lasting, and mostly unsatisfactory [27]. Therefore, it can be assumed that the quality of life of patients suffering from keloids and hypertrophic scars may be severely impaired. However, until now, no investigation on the impairment of the quality of life in these patients has been published.

Rapp et al. [24] showed that patients with psoriasis vulgaris feel the same reduction in quality of life as patients with life-threatening diseases like severe heart failure. This emphasizes the importance of investigations of quality of life. In recent years, the psychological aspects of skin diseases have become more evident. Patients suffering from pathological scarring not only realize their skin symptoms but they also recognize the psychological consequences.

Table 5 Correlation of the two scales "psychological impairment" and "physical impairment" with other parameters (correlation and ANOVA regarding sex and visibility)

Pearson-correlation	Mean (M) and SD	Scale 1		Scale 2	
		Corr	P	Corr	P
Pruritus	M = 0.95 SD = 2.87	0.18	0.07	0.76	≤ 0.001
Pain	M = 3.38 SD = 3.03	0.21	0.04	0.56	≤ 0.001
Restriction of mobility due to disease	M = 1.98 SD = 2.5	0.23	0.02	0.51	≤ 0.001
Intensity of disease	M = 2.30 SD = 1.14	0.25	0.01	0.24	0.02
Suffering from disease	M = 3.31 SD = 1.45	0.64	≤ 0.001	0.39	≤ 0.001
Age	M = 36.07 SD = 17.24	−0.01	0.93	0.25	0.01
Duration of disease	M = 7.18 SD = 6.55	−0.07	0.49	0.04	0.68
ANOVA		Mean/SD	P	Mean/SD	P
Sex (F = Female, M = Male; range from −5 = totally inaccurate until 5 = completely accurate)		F = −0.57/1.39 M = −1.00/1.53	0.16	F = −0.08/1.52 M = −0.42/1.67	0.31
Visibility (head, lower arms and lower legs, V = visible, NV = nonvisible; range from −5 = totally inaccurate until 5 = completely accurate)		V = −0.15, NV = −0.91	0.02	V = 0.12, NV = −0.30	0.25

The mean age of our patients was 36.1 years (median: 32.00) as shown in Table 1. One reason for this young age could be that younger people have a higher tendency to seek treatment for their scars. A review of the literature showed that the first manifestations of keloids occur at a median age of 22.3 (female) and 22.6 (male) years, respectively. Therefore, the mean age of our study population correlates with the typical age for keloid patients as described in the literature [9]. We found good psychometric properties of both our scales. First, they are relatively independent from each other, and second, both the timeless internal consistency (Chronbach's alpha) and the time-dependent retest-reliability were sufficient.

We found a lower number of male patients in our sample (34%). Shaffer et al. [27] described that keloids are found equally in male and female patients. Therefore, it may be assumed that female patients are more likely to seek treatment for their scars. The mean duration of disease was found to be 7.2 years. This long duration underlines the relevance of pathological scars to the quality of life of affected patients. In addition, the patients did not expect any convincing improvement of the clinical appearance of the scars, as these scars show a high resistance towards treatment [10, 29]. Most patients who underwent treatment for their scars realize that the therapeutic effect would be inadequate. This is another important factor influencing quality of life.

Table 2 shows which part of the body was affected by keloids and hypertrophic scars. Seventy-five percent of the scars were localized in the presternal area. Cohen et al. [9] pointed out that this area is most commonly affected by keloids.

Our results showed that quality of life of patients with keloids and hypertrophic scarring could be described by two scales: ''psychological impairment'' and ''physical impairment.''

Scale 1 reflected the psychological impairment of the patients (e.g. item 7 ''I do my best to prevent even people close to me from knowing that I have scars'' or item 11 ''I don't visit the swimming pool or the sauna since other people could feel disgusted because of my scars'').

Scale 2 reflected the physical impairment (e.g. item 2: ''My scars restrict my mobility'' or item 6 ''I find it difficult to put up with the itching caused by my scars'', cf. Table 3).

The items of the scale ''psychological impairment'' describe activities patients avoid due to their scars (e.g. ''I don't visit the swimming pool or the sauna since other people could feel disgusted because of my scars''). These items clearly describe the decreased quality of life of these patients. They recognize rejection and loss of self-confidence. In addition, they try to hide their scars (e.g. '' I do my best to prevent even people close to me from knowing that I have scars''). Being ''different'' is extremely difficult in cases in which skin lesions cannot be covered or hidden, as in patients with pathological scarring of visible body areas [25, 26]. The scale ''physical impairment'' includes the clinical symptoms related to pathological scarring. Patients suffer from itching and pain caused by the scars (e.g. ''I find it difficult to put up with the itching caused by my scars'' and ''Changes in the weather seriously affect my scars [pain, feeling of tension]'').

The data displayed in Table 4 clearly show that this new questionnaire is not influenced by specific social or demographic parameters like gender, age and duration of disease, except for a weak relationship between scale 2 and age. Therefore, it can be assumed that this new questionnaire to measure quality of life is largely independent of these variables. The high relation to items of clinical symptoms suggests sufficient external validity of the scales. This is supported by the close relation to visibility as compared to patients with psoriasis [25, 26]. This could be due to the higher awareness of scars in society as compared to psoriasis.

Relations (Pearson-correlation) between the scales ''psychological impairment'' and ''physical impairment'' and different, disease-characterizing single items, are also shown in Table 5. ''Suffering from disease'' showed a high correlation to scales 1 and 2. ''Restriction of mobility due to disease'' showed a marked correlation to scale 2. Restriction of mobility is a severe physical handicap. This item correlates with scale 2 and therefore influences quality of life. The results suggest that clinical symptoms of keloids and hypertrophic scars can be characterized by scale 2 (Pearson-correlation between scale 2 and pruritus is 0.76). Visible scars on the head, lower arms, or lower legs significantly influenced scale 1 psychological impairment implying the role of visible scars as an important stigma.

As decorative piercing is more often used particularly in younger age groups and in visible anatomical sites the number of hypertrophic scars and keloids is increasing [18]. In addition, satisfactory treatment options are still lacking as well as clinical studies using placebo-controlled, evidence-based designs [22]. Many approaches have been used to treat keloids resulting in international guidelines or new approaches [7, 23].

In conclusion, the results of this study demonstrate for the first time a severe impairment of quality of life of patients suffering from keloids and hypertrophic scars. The results suggest that the new questionnaire enables physicians to measure the quality of life in these patients. In addition, this questionnaire could be used to document the impact of new developments in the treatment of pathological scarring on quality of life. Further studies in this field should also include patients with normal scarring as a control group as a further support of the validity of the scale shown in this study.

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