

A pilot study of body image dissatisfaction and the psychological impact of systemic sclerosis-related telangiectases

H. Ennis¹, A.L. Herrick², C. Cassidy², C.E.M. Griffiths³, H.L. Richards⁴

¹Arthritis Research UK Epidemiology Unit, University of Manchester, Manchester Academic Health Science Centre, Manchester, United Kingdom;

²The University of Manchester, Manchester Academic Health Science Centre, Salford Royal NHS Foundation Trust, Salford, United Kingdom;

³The Dermatology Centre, The University of Manchester, Manchester Academic Health Science Centre, Salford Royal NHS Foundation Trust, Manchester, United Kingdom;

⁴Department of Clinical Health Psychology, Mercy University Hospital, Cork, Republic of Ireland.

Holly Ennis, PhD

Ariane L. Herrick, FRCP

Claire Cassidy, MBChB

Christopher E.M. Griffiths, FRCP

Helen L. Richards, PhD

Please address correspondence and reprint requests to:

Dr Holly Ennis,

Arthritis Research UK Epidemiology Unit, University of Manchester, Stopford Building, Oxford Road, Manchester M13 9PT, United Kingdom. E-mail: holly.ennis@manchester.ac.uk

Received on December 21, 2011; accepted in revised form on September 5, 2012.

Clin Exp Rheumatol 2013; 31 (Suppl. 76): S12-S17.

© Copyright CLINICAL AND

EXPERIMENTAL RHEUMATOLOGY 2013.

Key words: telangiectases, body-image dissatisfaction, quality of life, systemic sclerosis

Funding: this work was funded by the Raynaud's and Scleroderma Association
Competing interests: none declared.

ABSTRACT

Objectives. To determine the extent of body image dissatisfaction (BID) in patients with self-reported systemic sclerosis (SSc)-related telangiectases and to identify the demographic, psychological and disease-related correlates of BID within a cross-sectional study.

Methods. Patients with SSc were invited to participate in a questionnaire survey. Each completed the Adjusted Satisfaction with Appearance Scale (ASWAP), the Hospital Anxiety and Depression Scale (HADS) and an open-ended telangiectases questionnaire. Thematic analysis was utilised to describe the qualitative data.

Results. 141 patients with SSc participated (83% female, 70% limited cutaneous SSc, median age 62 years). Telangiectases were reported by 113 (80%). ASWAP 'dissatisfaction with appearance' scores were significantly higher in those reporting telangiectases ($p=0.02$). Anxiety and depression scores were similar in those with and without telangiectases. Those reporting telangiectases were more likely to be anticentromere positive (40% vs. 18%, $p=0.02$) and to have a history of severe digital ischaemia (38% vs. 18%, $p=0.04$) than those not. Qualitative analysis revealed four themes: changes in behaviour as a result of telangiectases, public and private self-image, negative emotional impact of telangiectases and appreciation of life.

Conclusions. BID, as measured by the ASWAP 'dissatisfaction with appearance' subscale, was significantly higher in patients with telangiectases. Telangiectases were associated with anticentromere positivity and digital ischaemia, lending further support for telangiectases as a potential marker for vascular involvement. Qualitative analysis provided new insights into the thoughts and feelings of patients with telangiectases. Our findings highlight the im-

portance of telangiectases and the need to address and manage related concerns.

Introduction

Both the limited and diffuse cutaneous subtypes (1) of the multisystem disease systemic sclerosis (SSc) are associated with progressive appearance-related changes that vary considerably between individuals and may also fluctuate over time. Telangiectases, which are abnormalities of microvessels caused by dilatation of primarily the post-capillary venules, represent one of the most visible physical manifestations of SSc. They occur commonly on the face, necklace area and upper limbs and are part of the microvascular pathology which is a major contributor to the SSc disease process (2), representing the 'T' in CREST (the term formerly used for the limited cutaneous subtype of SSc [lcSSc]). Although telangiectases affecting the skin (3) are by no means life-threatening, unlike many of the other clinical manifestations of SSc, their highly visible nature may adversely affect body image in affected patients.

Body image dissatisfaction (BID) represents a subjective construct (4) consisting of beliefs and feelings about perceived body image in contrast to an ideal, or a previously held, body image that is subject to change by social influences and attitudes. Although early studies of BID focused predominantly upon the healthy body and on eating disorders, there has been growing interest in recent years in acquired and highly visible conditions such as burn injuries and trauma (5-6). To date, the progressive physical changes in appearance associated with chronic disease, and anxiety over the wider social response to these changes, have attracted less attention yet appear to be related to psychological distress and low self-esteem (7-9).

Perceived attractiveness in patients with SSc has been shown to be a signifi-

cant predictor of anxiety and depression (10) and BID is especially important amongst younger women with SSc (11). Skin deformities have been identified as one of the most disturbing aspects of SSc although the impact of skin appearance is less clear-cut (12). Clinician-assessed skin thickness using the modified Rodnan skin score has been associated with increased dissatisfaction with appearance and social discomfort (13), although another study found that skin score was only weakly associated with psychosocial adjustment (14) and, elsewhere, no association at all was found between skin thickness and appearance self-esteem (12).

In a previous study, we reported a non-significant trend between increasing telangiectases severity and increased psychological distress (15). However, to date no studies have specifically examined the impact of SSc-related telangiectases on BID, or assessed the perceptions of affected patients although a recent study examining body image distress in SSc generally found an association between the presence of upper-body telangiectases and greater social discomfort (13).

In this study our overall aim was to test the hypothesis that, amongst patients with SSc, greater BID would be endorsed in those patients with self-reported telangiectases than those without. Specific objectives were to:

1. Determine the extent of BID in patients with SSc-related telangiectases.
2. Identify demographic, disease-related and psychological correlates of BID in patients with SSc-related telangiectases (hypothesising, with respect to psychological correlates, that there would be a positive association between BID and depressive symptoms).
3. Examine the perceptions of those with telangiectases using a qualitative approach.

Methods

Patients aged over 18 years of age with a confirmed diagnosis of lcSSc or diffuse cutaneous SSc (dcSSc) were identified via a clinical database at Salford Royal NHS Foundation Trust, and in-

vited to take part in a questionnaire survey. Those who wished to participate completed a set of three questionnaires and returned them, together with signed informed consent, to researchers by mail. A single reminder letter was sent to all non-responders 4-6 weeks after the initial mailing.

Measures

Three measures were used to assess the impact of telangiectases. These consisted of:

- a) Adjusted Satisfaction with Appearance Scale (ASWAP): A 15-item questionnaire designed to measure 'body image dissatisfaction' at multiple body sites and 'social discomfort related to appearance' (16), and validated for patients with SSc (17). Patients are asked to rate the degree to which each item accurately reflects their thoughts and feelings about their appearance on a Likert scale from 1 to 7, which was then converted to scores between 0 and 6, generating two subscale scores of 0 to 48 ('dissatisfaction with appearance') and 0 to 40 ('social discomfort') and a total score of 0 to 90, with higher scores indicating greater dissatisfaction and distress. Internal consistency (coefficient alpha) of the ASWAP scores in the current study was 0.73 for 'dissatisfaction with appearance', 0.71 for 'social discomfort' and 0.71 for the total score.
- b) The Hospital Anxiety and Depression Scale (HADS) (18): A 14-item scale assessing anxiety and depression in medical and surgical populations with each item scored between 0 and 3, allowing scores ranging from 0 to 21 for each subscale with higher scores indicating greater levels of distress and depression. The ability of the HADS to provide reliable indications of anxiety and depression has been well-documented and the measure has also been applied within previous studies of SSc (19, 10). Internal consistency (coefficient alpha) of the HADS scores in the current study was 0.80 for the anxiety score and 0.90 for the depression score.
- c) Telangiectases questionnaire: An 11-

item questionnaire containing items generated specifically for the current study through patient report, available literature and expert review. Four initial questions collected information about marital and employment status, whether patients were affected by telangiectases and the location of telangiectases by zone: face, mouth, neck, hands and arms (more than one areas could be listed). The measure then gathered information about the concerns and experiences of patients with telangiectases through a series of 7 open-ended questions: 'Do you ever try to cover up your telangiectases?', 'How do you feel your telangiectases affects your relationships with friends/family/new people', 'How do you feel your telangiectases affect the way you interact with the public/people in general?', 'How do feel your telangiectases affect your self-image?', 'How would you describe your appearance in light of your telangiectases?', 'What feelings and emotions do you have as a result of your telangiectases?' and 'How do your telangiectases affect your lifestyle?'.

Clinical data

Following informed written consent, medical records for all patients were accessed via a clinical database. Variables consisted of gender, ethnicity, age at assessment, age at onset of first non-Raynaud's clinical feature, disease duration since first non-Raynaud's clinical feature, subtype (lcSSc or dcSSc), presence or absence of severe digital ischaemia (as judged by a history of treatment with intravenous vasodilators, digital debridement or amputation) and anticentromere antibody status.

Ethical approval

Ethical approval was granted by the Wrightington, Wigan and Leigh National Research Ethics Service (NRES) UK Committee. Permission was sought for a member of the direct clinical team to access a limited dataset using a research database. Once consent was obtained, a more detailed dataset was extracted for use by the research team.

Table I. Respondent characteristics (n=141).

	Overall n=141	Telangiectases n=113	No telangiectases n=28	p-value (telangiectases vs. no telangiectases)
Female, n (%)	117 (83)	96 (85)	21 (75)	p=0.21
White Caucasian, n (%)	136 (96)	109 (96)	27 (96)	p=0.99
Married/cohabiting, n (%)	98 (70)	78 (69)	20 (71)	p=0.65
Retired, n (%)	94 (67)	80 (71)	14 (50)	p=0.06
Median age in yrs (IQR)	62 (14)	63 (14)	60 (10)	p=0.35
Median age at onset first non-RP feature, yrs, (IQR)	46 (20)	46 (21)	48 (19)	p=0.61
Median duration of disease since onset, yrs (IQR)	11 (12)	12 (12)	9 (12)	p=0.07
LcSSc, n (%)	100 (70)	81 (72)	19 (68)	p=0.69
History digital ischaemia, n (%)	48 (34)	43 (38)	5 (18)	p=0.04
Anticentromere positivity, n (%)*	50 (35)	45 (40)	5 (18)	p=0.02
ASWAP Total score, median (IQR)*	36 (21)	37 (20)	26 (22)	p=0.09
ASWAP Dissatisfaction with appearance, median (IQR)*	20 (12)	21 (12)	15 (12)	p=0.02
ASWAP Social Impact, median (IQR)*	14 (14)	14 (14)	12 (13)	p=0.66
HADS Anxiety, median (IQR)**	7 (6)	7 (6)	8 (8)	p=0.46
HADS Depression, median (IQR)**	6 (6)	6 (6)	6 (6)	p=0.52

*138. **140.

Data analysis

The ASWAP and HADS were scored according to published instructions (15-16). Variables did not meet the criteria for normal distribution and therefore were analysed using non-parametric methods. Medians and interquartile ranges were used to describe these data. Spearman's correlations, χ^2 and Fisher's test accordingly were employed to investigate the relationship between variables and differences between groups were examined with Mann Whitney U comparisons. Analyses were performed using SPSS Version 16.0.

The qualitative data arising from the telangiectases questionnaire were analysed by thematic analysis (20) undertaking the following steps: (i) the identification of themes emerging directly from the raw data; (ii) utilising a systematic method to clearly identify themes; and (iii) checking the analysis for reliability. Thus initially a process of reading and rereading the free text was undertaken (HE, HLR) with a view to familiarisation with the data and recognising themes submerged within the data. From this a list of all emerging themes was developed (HE). Through discussion between two of the authors (HE, HLR), themes were reviewed and related themes were subsequently

organised into 'clusters' in an effort to establish super-ordinate categories. Relevant quotations were highlighted and grouped under each theme. A description of each of the themes was then developed and headings identified which best described each of them. Finally the themes were checked against the original raw data. At each stage, the thematic arrangement and chosen illustrative quotations were discussed, expanded and agreed upon by the authors (HE, HLR) in an effort to eliminate personal researcher bias, promote validity of the results and achieve rigor.

Results

Recruitment and baseline characteristics

A total of 227 patients were contacted. Of these, 141 (62%) agreed to participate in the study. A further 5 (2%) did not wish to participate and the remainder did not respond. Potential differences between respondents and non-respondents were examined. The two groups did not differ significantly by gender or subtype, although age nearly reached statistical significance (respondents' median age=62 years, non-respondents' median age=57, $p=0.06$). The demographic and clinical characteristics of the 141 respondents are shown in Table I. Telangiectases were reported

by 113 (80%) respondents. The majority of respondents were married or cohabiting (70%) and were retired (67%). No significant demographic differences were detected between those with and without self-reported telangiectases. Respondents with telangiectases were more likely to be anticentromere positive (40% vs. 18%, $p=0.02$) and have a history of severe digital ischaemia (38% vs. 18%, $p=0.04$) than those without. The location of telangiectases was provided for all but one respondent: 30 face and mouth; 1 neck only; 8 face, mouth and neck; 2 hands only; 2 hands and arms; 9 face, mouth, neck, hands and arms and 60 combinations involving both the upper limbs and face, mouth or neck area.

Body image dissatisfaction (BID)

The interquartile range (Table I) indicated considerable variation in respondents' ASWAP scores. Median 'dissatisfaction with appearance' scores were higher in respondents with telangiectases than those without (21 vs. 15, $p=0.02$).

Anxiety and depression

The interquartile range again indicated considerable variation (Table I) in respondents' HADS scores but there was no significant difference in median scores between those with and without telangiectases in either the anxiety (7 for those with telangiectases vs. 8 without, $p=0.46$) or depression (6 for those with telangiectases vs. 6 without, $p=0.52$) subscales.

Associations between BID and demographic and clinical variables

Respondents with dcSSc had significantly higher total ASWAP and 'dissatisfaction with appearance' median subscale scores than those with lcSSc (39 in dcSSc vs. 34 in lcSSc, $p=0.03$ and 23 vs. 18, $p=0.003$ respectively). Respondents who were not married or cohabiting had significantly higher ASWAP scores than those who were: ASWAP total (42.5 vs. 33.5, $p=0.01$), 'dissatisfaction with appearance' (23 vs. 18, $p=0.05$) and 'social impact' (17.5 vs. 13, $p=0.02$) respectively. Respondents who had retired had sig-

nificantly higher scores only for the 'dissatisfaction with appearance' scale versus those who were not retired (21.5 vs. 16, $p=0.02$). In terms of the location of telangiectases, ASWAP scores differed significantly only for those with affected arms versus not (total ASWAP median score 24 in those with telangiectases on the arms vs. 18 in those without, $p=0.04$; 'dissatisfaction with appearance' median score 45 vs. 33, $p=0.01$; 'social impact' median score 19 vs. 13, $p=0.09$ respectively). A negative correlation was also found between both age and age at onset of first non-Raynaud's clinical feature ($p=0.01$ and $p=0.04$ respectively) and the ASWAP 'social impact' subscale score, indicating higher scores were reported by younger respondents.

Associations between anxiety and depression, and demographic and clinical variables

No associations were detected between either of the HADS scores and any of the clinical or demographic variables.

Qualitative data analysis

All respondents with telangiectases ($n=113$) provided qualitative data. Examination of these data provided a pattern of themes detailing individuals' personal and social responses to telangiectases. From the analysis, 4 themes emerged: 'changes in behaviour as a result of telangiectases', 'public and private self image', 'negative emotional impact of telangiectases' and 'appreciation of life'. The themes, and illustrative quotations, are detailed below. For presentation purposes, illustrative quotes have had spellings corrected and any changes made to the quote by the authors are illustrated in square brackets. Figures in round brackets after illustrative quotes indicate the number of the participant from whom the quote arose.

Theme 1: Changes in behaviour as a result of telangiectases

The visible nature of telangiectases appeared to impact upon respondents and many individuals described changing their behaviour as a result. Participants responded that they felt the need to

explain their condition or provide information to others in relation to their telangiectases: "I usually explain what it is" (208), "[I] answer questions for people ask me what it is" (193) and "I feel I have to explain to people it's not a rash" (25). Others reported compensating for their appearance: "I tend to hold my head down. I do my best to appear light-hearted and amusing" (115). For many respondents, changes in behaviour arose through forms of avoidance. These included: social avoidance *e.g.* "I tend to avoid people because I think I look like death warmed up" (132); and avoidance of reminders to the self of appearance *e.g.* "it's something I can live with as long as I stay away from mirrors" (83). For others the use of makeup and/or camouflage make-up was described as being a necessity: "[I] do not venture out without makeup" (115); "I wear foundation and then powder everyday and would not go out until I have put them on" (130). For some respondents the use of make-up was seen as an important means of coping with telangiectases *e.g.* "nobody has ever commented – I always wear cover" (218); "not a problem – just a make-up solution" (79); and "if I don't use it I'm told I look poorly and so I use it every day and do not go out with out it [make-up]" (140).

Theme 2: Public and private self image

At an individual level many respondents said they felt self-conscious because of their telangiectases: "[I] feel very self conscious. I feel they are very unattractive" (2) and "I hate the way I look...I do feel very self conscious and unattractive" (1). This was particularly evident for individuals when meeting new people: "I feel shy in front of new people and feel like people are looking at me" (224); and "with new people I feel self conscious and withdrawn" (161).

For many individuals there was a perception of a noticeable difference in appearance when in the public domain with respondents feeling they are being stared at: "I don't feel confident as I feel people are staring at red blotches" (19); "I feel self-conscious of my face and nose and feel as though people are staring or noticing the blemishes" (52) and

"People look at telangiectases instead of me" (7). For some this bordered on feeling stigmatised: "...sometimes they look at you as if you have the dreaded lurgy" (113); "I hate photographs being taken as I look like a drunken layabout, all red nosed with the hangover" (83); "A number of times people thought I had measles or chicken pox" (19); and "I try to explain it's not contagious" (28).

Theme 3: Negative emotional impact of telangiectases

The negative emotional impact specifically related to their telangiectases emerged as a theme for a number of participants. The emotions reported included: "I feel different, aggressive... it makes me feel depressive and of low self-esteem" (174); "I feel stupid" (213); "feelings of sadness and loss of confidence" (185); "I feel like crying a lot. I hate them and I wish they were somewhere else on my body" (224); "I feel quite ugly" (154).

Theme 4: Appreciation of life

Participants also described an appreciation of life despite their SSc and telangiectases. For some, it concerned their outlook on life: "...it is the person that is important – not how we look" (151) and "although myself more aware of many imperfections I try to take positive measures" (180); "Life is precious so I don't want to spend it feeling constantly sorry for myself" (83). For others this was associated with relationships: "my family are very supportive" (185); "my husband tells me after 30 years of marriage we are the same people inside we just have different wrappers" (30). Some individuals recognised both the negatives and changes in outlook: "[I] continue to cope with everyday life but in many ways I am limited but thankful [I am] still able to walk and go outside" (180); "some days I feel depressed at the way I look but I feel that is far less important than feeling well and being able to get about" (136).

Discussion

In our study of 141 patients with SSc, respondents with self-reported telan-

giectases had higher ASWAP 'dissatisfaction with appearance' subscale scores indicating greater BID. ASWAP median scores for all respondents were similar to published mean scores in a SSc sample (including both limited and diffuse subtypes) in the 'dissatisfaction with appearance' subscale (21 in the present study vs 24) and 'social impact' subscale (14 in the present study vs. 12) (17), suggesting that our patients were comparable to other SSc cohorts. Consistent with previous reports, patients with telangiectases were more likely than those without to be antinuclear antibody positive (21). Also, patients with telangiectases were more likely to have severe digital ischaemia (as judged by a history of treatment with intravenous vasodilators, digital debridement or amputation), further supporting the suggestion that telangiectases may serve as a potential clinical marker for vascular involvement as suggested by Shah *et al.*; data on pulmonary arterial pressure measurements were not collected as part of our study (22).

Respondents with dcSSc had significantly higher scores in the ASWAP total score and 'dissatisfaction with appearance' subscale ($p=0.03$ and $p=0.003$). The proportion of telangiectases was similar in those with lcSSc and dcSSc (81% vs. 78%) and the higher ASWAP scores in patients with dcSSc, consistent with existing research (17), may reflect the rapid onset of changes in appearance often experienced by patients with dcSSc, whose disease can evolve very rapidly. Although ASWAP scores can be influenced by ethnicity (23), this is unlikely to have been an issue in our cohort, most of whom were Caucasian ($n=96\%$).

The themes arising from the qualitative analysis, therefore, both complement and allow an enhanced understanding of findings elicited from the quantitative research reported above and are generally in lines with previous studies in the area. In particular the themes of 'changes in behaviour' and 'public and private self-image' mirror similar themes associated with avoidance and stigmatisation previously reported (24). Of particular interest within this

population was the emergence of the theme reflecting 'appreciation of life'. It is increasingly understood that there is a traumatic potential to serious illness (*e.g.* Odegard *et al.* (25)). However many individuals also report various positive changes, often referred to in the literature as Post Traumatic Growth (PTG), which reflect the processes of beneficial psychological adjustment and personal growth and have been linked to better coping with the disease-related demands (26-28). Indeed it is clear from the current study that negative responses in terms of psychological distress and BID are not inevitable for individuals with telangiectases and it would be of interest to examine how PTG is related to different disease variables and the emergence of such psychological factors.

There are a number of important limitations to this study. The methodology chosen was a postal survey and, therefore, selection bias was inherent within the study design. However, no significant differences were identified between respondents and non-respondents in terms of age, gender or subtype. It is possible that patients with SSc-related telangiectases were over-represented in the survey: 80% of respondents in the current study reported having telangiectases and, while this is higher than the 56% prevalence reported within a Japanese cohort by Ashida *et al.* (29), it is similar to the 78.9% reported by Jewett *et al.* within a Canadian cohort (13). Although information sheets and questionnaires emphasised that the study was open to both those with and without telangiectases, those without may have decided not to participate. Patients with more severe disease may also have been less likely to participate.

Within the current study, anxiety and depression were assessed by the HADS and, while scores varied considerably, the median scores were within normal ranges and no association was found between any of the clinical or demographic variables assessed within our study. While further studies using more detailed measures or structured clinical interviews may be indicated, existing literature suggests that high levels of depressive symptoms, in particular, are

associated with disease severity and internal organ involvement (30-31), variables not assessed within the current study.

The presence and absence of telangiectases was determined in all cases by respondents: we were interested specifically in patients' *perception* of their telangiectases, on the basis that this is what is likely to be important in terms of BID and psychological impact. It is possible that over – or under-reporting could therefore have occurred although information sheets did describe and define telangiectases. There was no attempt to collect information about the spread, size or vividness of telangiectases and this may have provided further insight into the impact of these lesions on BID. Current literature on BID indicates that the extent and severity of disfigurement does not, however, predict greater psychological distress (5, 32) and the qualitative comments we report indicate that other factors, such as ease of concealment or the attitude of family and friends, are of greater importance to respondents. Co-morbidity and the range of physical manifestations associated with SSc (including skin thickening, contractures and digital ulceration) may also have influenced the study results by impairing BID for reasons other than telangiectases. We tried to overcome this by specifically asking about the impact of telangiectases in both the information sheets and questionnaires used. Qualitative data also indicated that respondents believed their telangiectases varied considerably not only over periods of weeks and months, but also on a day-to-day basis. Prospective studies, examining change over time and the correlates of this, would be of interest from both a body image and pathophysiology perspective.

A strength of this study is the qualitative aspect which, for example, through questions asking specifically about efforts to cover up telangiectases, indicated widespread concern about appearance, the perceptions of others within society and unhappiness with the perceived necessity or process of covering up telangiectases. While the methods of collating the qualitative data may be restricted by the postal survey method

utilised, nonetheless the qualitative aspect provides insight into the thoughts and feelings of those with SSc regarding their physical appearance and the variability that exists in terms of the appearance and severity of telangiectases. In summary, as well as being a marker of vascular disease severity, SSc-related telangiectases are important because of their impact on body image. Clinicians should therefore not dismiss cutaneous telangiectases as being a 'minor' clinical manifestation of SSc, but should listen to the patient's concerns and explore possible treatment options including laser or intense pulsed light therapy, or the use of cover or 'camouflage' cosmetics.

References

1. LEROY EC, BLACK C, FLEISCHMAJER R *et al.*: Scleroderma (systemic sclerosis): classification, subsets and pathogenesis. *J Rheumatol* 1988; 15: 202-5.
2. CAMPBELL P, LEROY EC: Pathogenesis of systemic sclerosis: a vascular hypothesis. *Semin Arthritis Rheum* 1975; 4: 351-68.
3. WALKER JG, STIRLING J, BEROUKAS D *et al.*: Histopathology and ultrastructural features of dermal telangiectases in systemic sclerosis. *Pathology* 2005; 37: 220-5.
4. GLEESON K, FRITH H: (De)constructing Body Image. *J Health Psychol* 2006; 11: 79-90.
5. LAWRENCE JW, FAUERBACH JA, HEINBERG L, DOCTOR M: Visible vs hidden scars and their relation to body esteem. *J Burn Care Rehabil* 2004; 25: 25-32.
6. PELLARD S: Body image and acute burn injuries: a literature review. *J Wound Care* 2006; 15: 129-32.
7. LONEY T, STANDAGE M, LEWIS S: Not just skin deep. Psychological effects of dermatological-related social anxiety in a sample of acne patients. *Health Psychol* 2008; 13: 47-54.
8. RUMSEY N, CLARKE A, MUSA M: Altered Body Image: the psychological needs of patients. *Br J Community Nurs* 2002; 7: 563-66.
9. JORGE RTB, BRUMINI C, JONES A, NATOUR J: Body image in patients with rheumatoid arthritis. *Mod Rheumatol* 2010; 20: 491-5.
10. RICHARDS HL, HERRICK AL, GRIFFIN K, GWILLIAM PDH, FORTUNE DG: Psychological adjustment to systemic sclerosis exploring the association of disease factors, functional ability, body related attitudes and fear of negative evaluation. *Psychol Health Med* 2004; 9: 29-39.
11. BENRUD-LARSON LM, HEINBERG LJ, BOLING C *et al.*: Body Image Dissatisfaction among women with scleroderma: extent and relationship to psychosocial function. *Health Psychol* 2003; 22: 130-9.
12. VAN LANKVELD WJM, VONK MC, TEUNISSEN H, VAN DEN HOOGEN FHJ: Appearance self-esteem in systemic sclerosis – subjective experience of skin deformity and its relationship with physician-assessed skin involvement, disease status and psychological variables. *Rheumatology* 2007; 46: 872-6.
13. JEWETT LR, HUDSON M, MALCARNE VL, BARON M, THOMBS BD, CANADIAN SCLERODERMA RESEARCH GROUP: Sociodemographic and disease correlates of body image distress amongst patients with systemic sclerosis. *PLoS One* 2012; 7(3): e33281.
14. MALCARNE VL, HANSDDOTTIR I, MCKINNEY A *et al.*: Medical signs and symptoms associated with disability, pain, and psychosocial adjustment in systemic sclerosis. *J Rheumatol* 2007; 34: 359-67.
15. STYLIANIDES NA, BHUSHAN M, RICHARDS H, HERRICK AL: Telangiectases in systemic sclerosis – relationship to vascular disease severity and to psychological distress. *Rheumatology* 2003; 42 (Abstr Suppl. 1), 138.
16. LAWRENCE JW, HEINBERG LJ, ROCA R, MUNSTER A, SPENCE R, FAUERBACH JA: Development and validation of the Satisfaction With Appearance Scale: assessing body image among burn-injured patients. *Psychol Assessment* 1998; 10: 64-70.
17. HEINBERG LJ, KUDEL I, WHITE B *et al.*: Assessing body image with systemic sclerosis (scleroderma): validation of the Adapted Satisfaction With Appearance Scale. *Body Image* 2007; 4: 79-86.
18. ZIGMOND A, SNAITH R: The Hospital Anxiety and Depression Scale. *Acta Psychiatr Scand* 1983; 67: 361-70.
19. BJELLAND I, DAHL AA, TANGEN HAUG T, NECKELMANN D: The validity of the Hospital Anxiety and Depression Scale. An updated literature review. *J Psychosom Res* 2002; 52: 69-77.
20. BOYATZIS RE: Transforming qualitative information. London Sage 1998.
21. STEEN V, POWELL D, MEDSGER T: Clinical correlations and prognosis based on serum antibodies in patients with systemic sclerosis. *Arthritis Rheum* 1988; 31: 196-203.
22. SHAH A, WIGLEY F, HUMMERS L: Telangiectases in scleroderma: a potential clinical marker of pulmonary arterial hypertension. *J Rheumatol* 2010; 37: 98-104.
23. REEKIE T: The effect of South Asian ethnicity on satisfaction with primary cleft lip and or palate repair. *J Plast Reconstr Aesthet Surg* 2011; 64: 189-94.
24. JOACHIM G, ACORN S: Life with a rare chronic disease : the scleroderma experience. *J Adv Nurs* 2003; 42: 598-606.
25. ODEGARD S, FINSET A, MOWINCKEL P, KVIENTK, UHLIG T: Pain and psychological health status over a 10-year period in patients with recent onset rheumatoid arthritis. *Ann Rheum Dis* 2007; 66: 1195-201.
26. BARSKOVA T, OESTERREICH R: Post traumatic growth in people living with a serious medical condition and its relations to physical and mental health : a systematic review. *Disabil Rehabil* 2009; 31: 1709-33.
27. FORTUNE DG, RICHARDS HL, GRIFFITHS CEM, MAIN CJ: Adversarial growth in patients undergoing treatment for psoriasis: A prospective study of the ability of patients to construe benefits from negative events. *Psychol Health Med* 2005; 10: 44-56.
28. CALHOUN LG, TEDESCHI RG: The foundations of posttraumatic growth: an expanded framework. In: CALHOUN LG, TEDESCHI RG, editors. *Handbook of Post-traumatic Growth: Research and Practice*. Mahwah, NJ: Erlbaum; 2006. pp 3-23.
29. ASHIDA R, IHM H, MIMURA Y *et al.*: Clinical and laboratory features of Japanese patients with scleroderma and telangiectases. *Clin Exp Dermatol* 2009; 34: 781-3.
30. THOMBS BD, LANKVELD MV, BASSEL M *et al.*: Psychological health and well-being in systemic sclerosis : state of science and consensus research agenda. *Arthritis Care Res* 2010; 62: 1181-9.
31. THOMBS BD, HUDSON M, TAILLEFER SS, BARON M; CANADIAN SCLERODERMA RESEARCH GROUP: Prevalence and clinical correlates of symptoms of depression in patients with systemic sclerosis. *Arthritis Res Care* 2008; 59: 504-9.
32. RUMSEY N, HARCOURT D: Body image and disfigurement: issues and interventions. *Body Image* 2004; 1: 83-97.