

**UNDERSTANDING PSYCHODERMATOLOGICAL DISTRESS:  
CONSTRUCTING A SKIN SHAME SCALE**

Submitted by

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July 2004

Thesis submitted for the degree of Doctor of  
Clinical Psychology, to the Department of Psychology,  
University of Sheffield



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# **UNDERSTANDING PSYCHODERMATOLOGICAL DISTRESS: CONSTRUCTING A SKIN SHAME SCALE**

## **Literature Review**

This section offers a review of the literature concerning psychodermatological assessment, that is, the assessment of the interface between the skin and its psychological correlates, and evaluates selected psychodermatological scales. Using defined criteria, fifty articles were identified, including twenty-three scales, which are reviewed in detail. Findings demonstrated that quantitative self-report scales dominated assessment. When evaluated against psychometric and theoretical criteria, the scales were found to have limited robustness and validity. These findings are discussed in relation to the relationship between disease severity and skin-related distress and subsequent theoretical and clinical implications explored.

## **Research Report**

Living with a skin condition can lead to considerable psychological distress. Understanding the mechanisms of skin-related distress is crucial in developing a psychodermatological theory and devising meaningful psychological interventions. The



present study employed Kellett's (2002) theory of "dermatological shame" to construct a psychodermatological assessment scale for use in dermatological outpatient populations, in this case, at Barnsley District General Hospital dermatology department. The scale was subjected to exploratory factor analysis and reduced from thirty to twenty-four items. Reliability and validity analyses were then carried out and the results discussed in relation to dermatological shame and cognitive models of disfigurement (Kent & Thompson, 2002; Thompson & Kent, 2001).

### **Critical Appraisal**

A reflexive account is offered of the research process, through four sections: project conception, study implementation, learning and development, including methodological limitations, and process issues. This section concludes with recommendations for further research.

## **ACKNOWLEDGEMENTS**

Firstly, I should like to extend my thanks to the participants who gave their time and efforts to complete the questionnaires.

Secondly, I should like to thank the Barnsley District General Hospital dermatology team who helped bring this project to life.

Thirdly, my thanks go to Dr Kellett for his patience and motivation throughout this project and to Drs Kent and Thompson for their continued guidance and support. My thanks also go to my clinical supervisor, Dr Ellie Hurrell, for her understanding, encouragement and flexibility.

Lastly, and most importantly, I thank my Mum and Dad for the thirty-three years of love that have made this possible, and for inspiring the bigger picture that I hold so dear.

## **WORD COUNT**

The intended journal for submission of the literature review is the British Journal of Health Psychology, while the research report has been prepared under the guidelines for format B, for the journal Psychology and Health.

### **Literature Review**

Main body	7944
Reference Section	3663
Total	11607

### **Research report**

Main body	7679
Reference section	2680
Total	10359

### **Critical Appraisal**

Main body	4421
Reference section	488

Total 4909

Appendices (approx.) 4500

Total Word Count 31375

Total excluding References and Appendices 20044

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**PSYCHODERMATOLOGICAL ASSESSMENT: A LITERATURE REVIEW**

INTENDED JOURNAL FOR SUBMISSION: BRITISH JOURNAL OF HEALTH  
PSYCHOLOGY

WORD COUNT 7944

# PSYCHODERMATOLOGICAL ASSESSMENT: A LITERATURE REVIEW

## 1 ABSTRACT

**Objective** Approaches to psychodermatological assessment are evaluated and future directions discussed.

**Design** selective review of psychodermatological scales according to psychometric and theoretical criteria, using the terms “psycho dermatol\*”, “dermatol\*?psychol\* distress”, “ skin shame/assessment/measurement”.

**Method** Using defined search criteria, papers describing relevant scales were identified from BIOSIS, PsycINFO and Medline databases. Fifty papers were included and twenty-three scales reviewed.

**Results** Psychodermatological assessment is dominated by quantitative self-report questionnaires based on health-related Quality of Life (referred to as QoL). These scales have varying degrees of psychometric robustness and clinical utility, but crucially lack a theoretically coherent psychological base underlying them. Scale development has suggested that psychological factors play a pivotal role in skin distress, but existing scales may not reflect this adequately.

**Conclusion** Psychodermatological assessment is a-theoretical and underdeveloped. Findings are discussed in relation to assessing the psychological mediators of skin distress.

## **2 INTRODUCTION**

### **2.1 Aim**

The aim of this literature review is to provide a critical overview of existing assessment measures of psychological distress in dermatological conditions.

### **2.2 Overview**

What is it like to live with a skin condition? Can this experience be measured with any degree of reliability or validity? People whose appearance is significantly “different” from others have been found to be at increased risk of social anxiety, stigmatisation and shame (Ginsberg & Link, 1989, 1993; Jowett & Ryan, 1985; Kellett, 2002; Schmid-Ott, Burchard, Niederauer, Lamprecht & Kunsebeck, 2003; Thompson & Kent, 2001). There is growing interest in examining the psychological correlates of living with skin conditions, with a view to understanding and conceptualising this experience, and offering support where indicated and desired. A substantial body of literature has indicated that various skin conditions are associated with lowered mood and self-esteem, with long-term implications for quality of life (Papadopoulos, Bor, & Legg,

1999; Reilly, Lavin, Kahler, & Pariser, 2003; Tulloch & Ormerod, 2003). These effects appear independent of disease severity; minor skin blemishes may be related to severe distress in some people (Carr, Harris & James, 2001; Picardi & Abeni, 2001) while Finlay, Khan, Luscombe, & Salek (1990) found the psychological effects of severe psoriasis comparable with those of cardiac failure. Anxiety, depression (Gupta & Gupta, 2001; Hardy & Cotterill, 1982; Hughes, 1983; Linnet & Jemec, 1989; Millard, 2000; Sheehan-Dare, Cotterill, & Simmons, 1990) and suicidal ideation have also been reported (Cotterill & Cunliffe, 1997; Gupta, Schørk, & Gupta, 1993; Gupta & Gupta, 1998; Picardi, Abeni, Melchi, Puddu, & Pasquini, 2000).

The study of the interaction between the psyche and the skin has been termed “psychodermatology” (Gieler, 2003; Koo, 1995, 2000; Van Moffaert, 1982) and the psychosocial impact of skin disease well documented (Ginsberg, 1996; Gupta & Gupta, 1995, 1998; Koo, 1995). This review attempts to examine existing psychodermatological measures with the specific aim of critically reviewing (a) whether they satisfy defined reliability and validity parameters and (b) whether they facilitate biopsychosocial assessment. Biopsychosocial assessment refers to a holistic approach that takes into account the biological basis of skin disease, its psychological effects, and



social factors that may impact on the individual (Kellett & Gilbert, 2001). It is, therefore, of clinical utility.

### **2.3 Search strategy**

Papers were identified using two strategies: (1) BIOSIS, PsycINFO and Medline databases were searched with the terms “psycho dermatol\*”, “dermatol\*/psychol\* distress”, “skin shame”, “assessment” and “measurement”: and (2) references from published studies.

Papers from 1990-2004 were selected, concentrating on those published after the last related overview by Halioua, Beumont, & Lunel, (2000), which focused on dermatological QoL measurement only. Key papers published before 1990 are included. Papers were included if they were published in English, described psychodermatological measures, or reviewed psychodermatological measures. Studies that did not meet these criteria were excluded as the review focused on the psychological assessment of dermatological distress.

## 2.4 Rationale for Exclusions

As the review focused on self-reported psychodermatological measures, the following categories of scale were excluded: ratings of disease severity and coverage, measures aimed at children and families and approaches to assessing disfigurement<sup>1</sup>.

## 3 THE PREVALENCE OF SKIN CONDITIONS AND ASSOCIATED PSYCHOLOGICAL DISTRESS

In order to justify the need for the biopsychosocial assessment of skin conditions, it is crucial to underline the extent of skin disease and its associated distress. Patients' concerns about their skin account for about 10% of all consultations in UK general practice of which 75% are dealt with in primary care (Harlow, Poyner, Finlay, & Dykes,

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<sup>1</sup> Therefore, purely physiological measures like the Psoriasis Area and Severity Index (Fredrikson & Pettersson, 1978) and disfigurement scales, such as the Derriford Appearance Scale (DAS-59: Carr, *et al.*, 2001), were excluded because they have no specific psychodermatological items. The DAS-59 is not specific to skin-related distress, and health-related QoL measures, such as the Sickness Impact Profile (UKSIP: Bergner *et al.*, 1981) were excluded as they assess symptoms, rather than facilitating biopsychosocial assessment (McKenna, Cook, Whalley, Doward, Richards, Griffiths, *et al.*, 2003). Using these criteria, fifty papers were identified and twenty-three form the focus of this review, the others being review papers. It will begin with an examination of the impact of skin conditions. Dermatological assessment will then be introduced, before psychodermatological scales are evaluated.

2000; Hunter, Savin, & Dahl, 1989). The Lambeth study (Rea, Newhouse, & Halil, 1975) of the prevalence of skin diseases in the general population, found that 22.5% of the 2180 participants had skin conditions justifying medical attention. Eczema represented the largest group, with a prevalence of 9%. The remaining four most common diagnoses were acne, scaly dermatoses such as psoriasis, prurigo (chronic itching), and erythematous disorders (inflammation). US prevalence studies demonstrated that 312 people per 1000 population had one or more condition meriting evaluation by a dermatologist. The prevalence of skin conditions has been shown to peak in young adulthood at 365 per 1000 from 18-24 years (Weinstock & Chren, 2003; Williams, 1998) and rise from 34 years, reflecting the increase in chronic conditions such as psoriasis. Thus, skin conditions can potentially have a significant psychological impact across the lifespan.

These prevalence levels reflect a high rate of skin disorders, but what of the associated distress? Many dermatological conditions can lead to disfigurement, either directly through the disease process or indirectly, following treatment (Thompson & Kent, 2001). Some individuals may go on to develop psychological problems, as a consequence of disfigurement or other health issues (Koo, 1995) and the relating stigmatising reactions of others (Ginsberg & Link, 1989, 1993; Thompson & Kent,

2001). Studies of individuals with dermatological disfigurement have highlighted high levels of anxiety and depression (Jowett & Ryan, 1985), worthy of clinical intervention.

### **3.1 Why assess dermatological distress?**

Living with a skin condition has potential implications for physiological and psychological health and the impact of others' reactions makes psychodermatological assessment a biopsychosocial issue. Indeed, the literature showed that for some diseases, like melasma, the psychological impact might be greater than its physical effects (Balkrishnan, McMichael, Camacho, Saltzberg, Housman, *et al.*, 2003). Psychological assessment is necessary to inform effective interventions. Unless psychological aspects of dermatoses are addressed, treatment may prove ineffective (Williams, 1998) because interventions might not address clients' experiences and needs. As researchers have begun to investigate psychological problems associated with skin disease, this has inevitably necessitated the development of valid and reliable scales in order that clients can report their experiences. The development of such scales will now be examined.

### **3.2 How has dermatological distress been assessed?**

Psoriasis was the first skin condition to be assessed psychodermatologically, and its impact on patients' lives is well described (Finlay, 1997). Questionnaires exploring the subjective experiences of people with psoriasis (Jobling, 1976; Ramsay & O'Reagan, 1988) established that it could affect well-being outside the physiological domain. Dermatologists have responded by attempting to assess the adverse effects of skin disease on Quality of Life (QoL) using replicable self-report questionnaire-based scales (Finlay, 1997, 1998).

Although the first scales were disease-specific to psoriasis, they have become increasingly "dermatology-specific", generalisable to all skin conditions, as researchers have sought to reflect the specific difficulties of dermatological populations and compare different dermatoses. Scales have varying degrees of psychometric robustness (Finlay, 1997; Halioua *et al.*, 2000), though validation studies are typically piecemeal (Anderson & Rajagopalan, 1997), suggesting a dearth of psychometrically robust psychodermatological scales.

Assessment has become dominated by quantitative methodology. Though this is amenable to psychometric evaluation, the subjective experiences of individuals with skin disease remain poorly described and understood. Ginsberg & Link's (1989) approach to studying feelings of stigmatisation in psoriasis offered patients descriptions of experiences including guilt and shame, but the researchers generated these dimensions empirically, without recourse to theory. A subjective measure of disease activity by Lundberg, Johannesson, Silverdahl, Hermansson, & Lindberg, (2000) offered individuals the opportunity to describe their experiences but has not been applied clinically.

Despite the biopsychosocial nature of skin disease, the need for psychodermatological assessment has not always been recognised. This limited acknowledgement of the value of psychological input into dermatology services has clinical implications, although Gledhill, Keller-Jackson, & Cheesbrough, (1995) and Finlay (1997) described the positive evaluation of a clinical psychology service within a dermatology department. Attempts to develop clinical psychology services in dermatology outpatients have met with mixed results (Fortune, Richards, Main, O'Sullivan, & Griffiths, 1998). Thus the interface between psychology and dermatology remains underdeveloped.

Thus far, this introduction has suggested that dermatologists have driven psychodermatological assessment and that it is characterised by quantitative self-report scales with varying degrees of psychometric robustness and biopsychosocial relevance. In order to examine their value further, existing psychodermatological scales will now be evaluated.

#### **4 STRUCTURE OF REVIEW**

Previous overviews by Finlay (1997, 1998) and Halioua *et al.*, (2000) have been practically driven, describing QoL measures in dermatology and advising the reader on their clinical relevance. Others have been limited to dermatology-specific (de Tiedra, Mercadal, Badia, Mascaró, & Lozano, 1998) or disease-specific scales (de Korte, Mommers & Sprangers, 2002; McKenna & Stern, 1996) and have tended to ignore theoretical issues (de Tiedra *et al.*, 1998; Halioua *et al.*, 2000). This review will utilise Finlay's (1997) framework, adopted by Halioua *et al.* (2000), that categorised scales into dermatology (generic) and disease-specific scales, but will attempt to build on this by evaluating all psychodermatological scales including those developed since their reviews. Each scale will be evaluated using two key criteria:

- Psychometric Robustness: this will include an examination of the scales' validity, reliability, and sensitivity.
- Theoretical robustness, including an assessment of theory-practice links.

First, dermatology-specific scales will be evaluated, and then second, disease-specific scales evaluated by condition, under psoriasis, acne, eczema and miscellaneous categories. Common methodological and theoretical concerns and limitations will then be discussed and critical themes emerging from the literature highlighted. This will be followed by conclusions and implications for further studies.

## **5 PSYCHOMETRIC ROBUSTNESS CRITERIA**

In order to evaluate each scale consistently, it is critical to define each psychometric criterion carefully, after Cook & Campbell (1979), DeVellis (2003), Hays, Anderson, & Revicki, (1993) and Anastasi (1988). Firstly, reliability refers to the consistency with



which any scale assesses a trait or attribute. It is an important measurement concept because it relates to the practical utility of measures, as described below<sup>2</sup>.

<sup>2</sup> Criterion	Definition
<b>Temporal Stability</b>	The extent to which a person's perception is constant over time, it "shows the extent to which scores on a test can be generalised over different occasions; the higher the reliability, the less susceptible the scores are to the random daily changes in the condition of the test takers or of the testing environment" (Anastasi, p. 117).
<b>Internal Consistency</b>	The degree of homogeneity among items within a scale and their capacity to measure a single phenomenon. A scale is internally consistent when its items are highly correlated with each other, suggesting that all items are measuring a common construct. A scale may only be considered trans-culturally valid if it demonstrates acceptable levels of reliability and validity across different cultural groups (Hays <i>et al.</i> , 1993).
<b>Construct Validity</b>	The degree to which a scale's underlying structure can be identified and the extent to which such a structure reflects the theoretical model on which the scale is based.

These criteria will now be applied to the two categories of scales. With reference to the reliability and validity of the reviewed scales, a quality criterion of  $r = 0.80$  or above was used to indicate good reliability. It should be noted that statistically significant reliability and validity does not necessarily indicate that any scale possesses clinical utility. For this reason, factors crucial to utility, such as face and ecological validity and scale length are also discussed. For the purposes of psychometric evaluation, correlation

<b>Criterion Validity</b>	"The effectiveness of a test in predicting an individual's performance in specified activities" (Anastasi, p. 145). Criterion validity implies an empirical association between an item or scale and a "gold standard" criterion, whether or not the theoretical basis for that association is understood. DeVellis (2003) argues that criterion validity is the preferable standard of validity because it is temporally neutral.
<b>Content Validity</b>	The extent to which a set of items reflects a content domain, involving "the systematic examination of the test content to determine whether it covers a representative sample of the behaviour domain to be measured" (Anastasi, p. 140).
<b>Face Validity</b>	The capacity of a scale or item to appear meaningful to the reader.
<b>Ecological Validity</b>	The validation of related performance on a scale across samples and settings within the same society.
<b>Sensitivity</b>	The ability of any scale to reflect underlying changes over time.

coefficients were defined operationally as “high” at  $r = 0.80$  or above, “moderate” at 0.60-0.80 and “low” at 0.40 or below (Anastasi, 1988).

## **6 DERMATOLOGY-SPECIFIC SCALES**

These measures have attempted to assess the psychological manifestations of dermatological conditions and associated medical interventions (Halioua *et al.*, 2000). Those reviewed below have varying degrees of psychological or psychosocial content, addressing one or more dimensions of psychological functioning, e.g. mood, perceptions, behaviour or cognitive factors associated with skin distress. Each scale will be described briefly before being evaluated.

### **6.1 The Dermatology Life Quality Index (DLQI: Finlay & Khan, 1994)**

The ten-item DLQI purports to measure dermatology patient’s health-related QoL over the previous week from a broadly psychosocial perspective, using six subscales covering “symptoms and feelings”, “daily activities”, “leisure”, “work and school”, “personal relationships” and “treatment”.

Over 200 references have utilised the DLQI (Finlay, 2003) and most examinations of its psychometric robustness are favourable (Badia, Mascaro, & Lozano, 1999; Hahn, Melfi, Chuang, Lewis, Gonin, *et al.*, 2000). It has been utilized with most chronic skin disease populations, including psoriasis (Badia *et al.*, 1999; Mazzotti, Picardi, Sampogna, Sera, Pasquini, *et al.*, 2003; McKenna *et al.*, 2003; Mørk, Wahl, & Moum, 2002; Nichol, Margolis, Lipan, Rowe, & Quell, 1996; Touw, Hakkart-Van Roijen, Verboom, Paul, Rutten, *et al.*, 2001), acne (Mallon, Newton, Klassen, Stewart-Brown, Ryan *et al.*, 1991; Klassen, Newton, & Mallon, Newton, 2000), dermatitis (Eun & Finlay, 1990; Herd, Tidman, M. J., Ruta, D. A., & Hunter, 1997; Reilly *et al.*, 2003), atopic eczema (Finlay, 1987), vitiligo (Kent & Al-Abadie, 1996; Papadopoulos, Bor & Legg, 1999), melasma (Balkrishnan, McMichael, Camacho, Saltzberg, & Housman, 2003), dermatology outpatients (Jayaprakasam, Darvay, Osbourne, & McGibbon, 2002; Hahn, Melfi, Chuang, Lewis, & Gonin, 2000; Hongbo, Harrison, Salek, & Finlay, 2003a), inpatients (Mazzotti, Picardi, Sampogna, Sera, Pasquini, 2003), Behçets syndrome and Darier's disease, suggesting strong generalisability.

The DLQI has been shown to exhibit high test-retest reliability over 1 week:  $r = 0.99$ ,  $P < 0.0001$  (Finlay & Khan, 1994) and internal reliability from  $r = 0.23-0.70$  (Finlay & Khan, 1994). Independent studies have evidenced its internal consistency (McKenna *et*

*al.*, 2003; Zachariae, Zachariae, Ibsen, Mortensen, & Wulf, *et al.*, 2003) and one-week test-retest correlation ( $r = 0.93$ , Zachariae *et al.*, 2003).

The construct validity of the DLQI has been shown through comparisons with 200 dermatology outpatients and 100 controls (Finlay & Khan, 1994) and a random subsample of 30 patients with a sample population of 537 (Hongbo *et al.*, 2003a), although factor analysis (Kent & Al-Abadie, 1996) found no evidence for the existence of the 6 proposed dimensions, suggesting that the data were better described in 3 categories. The DLQI's criterion validity has been demonstrated with acne-specific scales, the Psoriasis Disability Index and the SF-36 (Lundberg, Johannesson, Silverdahl, Hermansson, & Lindberg, 2000) and it discriminates effectively between patients with different conditions (Finlay & Khan, 1994), inpatients and outpatients (Zachariae *et al.*, 2003), those whose psoriasis improved and those who remain unchanged (Mazzotti *et al.*, 2003), and vitiligo patients with successful outcomes and those with treatment failure. The low mean DLQI score of 0.5 for non-clinical controls demonstrated by Finlay & Khan in their original study suggests that it discriminates well between dermatological populations and healthy controls.

The DLQI is highly sensitive to a number of external criteria, including age of onset and global severity (Nichol, Margolis, Lipan, Rowe & Quell, 1996), (in contrast with other dermatology-specific scales, such as Skindex-29), to clinical improvement, especially in symptoms and feelings (Shikiar, Bresnahan, Stone, Thompson, & Koo, 2003) and to change after 4 months of pharmacological treatment in acne (Klassen *et al.*, 2000).

The DLQI appears to have face validity and is considered clinically useful (Jayaprakasam *et al.*, 2002). It has been applied in North America (Hahn *et al.*, 2000), translated into Norwegian (Mørk, Wahl, & Moum, 2002) and proposed as a standard measure in Spain (de Tiedra *et al.*, 1998). Swedish and Danish DLQI data are also available (Lundberg *et al.*, 2000; Zachariae *et al.*, 2003). However, evidence of the DLQI's trans-cultural validity is equivocal as its mean and standard deviation scores have differed greatly: Mazzotti *et al.* (2003) found a DLQI mean of 8.7+/-6.0 in an Italian dermatology sample, in contrast to Jayaprakasam *et al.*'s London study that yielded a mean of 4.9 +/- 4.4, suggesting that the DLQI may be unstable. Zachariae *et al.*'s (2003) Danish mean outpatient (7.9) and inpatient (12.9) scores were equivalent to the original English means of 7.3 and 13.2. Hahn *et al.* (2000) and Lundberg *et al.* (2000) found lower DLQI scores in U. S. and Swedish samples, though this may have been due to the lower disease severity. However, other studies have yielded

unexpectedly high and low mean DLQI scores of 18 (Finlay, 1997) and 4.82 (Kent & Al-Abadie, 1996), suggesting that it may be sensitive to changes in sample or skin condition. Furthermore, the DLQI has been applied in developed, Caucasian societies only. An illustrated version of the DLQI (Diba, Loo, Chawla, & Finlay, 2002; Loo, Diba, Chawla, & Finlay, 2003) that might be applied successfully trans-culturally and with people with hearing and literacy impairments has not demonstrated exact equivalence with the text versions, suggesting an absence of ecological validity.

The DLQI has other drawbacks: Herd *et al.*, (1997) demonstrated that while some items correlated moderately with the Patient Generated Index (Ruta, Allen, Herd, & Tidman, 1998), a semi-quantitative measure of health-related QoL, DLQI totals showed inverse correlations with the PGI. The apparently poor life quality shown by the PGI was not reflected in DLQI scores, because the PGI allows patients to state which aspects they feel are most impaired - a more ecologically valid approach. Perhaps the greatest psychometric weaknesses of the DLQI are that no normative data are available (Lundberg *et al.*, 2000) and that its sub-scales contain too few items to be considered reliable or valid. However, despite some limitations, the literature reflects the overall psychometric robustness of the DLQI in its widespread use as a criterion measure in

scale development (Clark, Allen, Herd, & Tidman, 1997; Balkrishnan *et al.*, 2003; McKenna *et al.*, 2003).

## **6.2 Skindex-29 (Chren, Lasek & Quinn, 1996)**

The 29-item Skindex is a relatively new, less widely tested dermatology-specific scale (de Korte *et al.*, 2002), containing five psychological dimensions. It has been found to be generalisable across skin conditions (Chren, Lasek, & Quinn, 1997a, 1997b), including acne (Lasek & Chren, 1998), melasma (Balkrishnan *et al.*, 2003) and general dermatology patients (Chren *et al.*, 1997a; Chren, Lasek, Flocke & Zyzanski, 1997b). It has been shown to have high test-retest reliability (0.88-0.92); internal consistency (0.87 to 0.96) and high internal reliability (0.96) for each scale in a large sample (Chren *et al.*, 1996; de Korte *et al.*, 2002) and was more sensitive to skin-related aspects of health than the SF-36 (Chren *et al.*, 1997b). The external criterion validity of Skindex-29 has been mixed: Balkrishnan (2003) demonstrated that Skindex-29 had less discriminative power between groups of women with psychological problems, than a melasma-specific scale derived from it, whereas Chren *et al.* (1996) found that patients with low, medium or high Skindex-29 scores differed similarly in SF-36 scores; however, some patients were free from social effects on the SF-36 recorded high Skindex-29 scores.



Its construct validity has been demonstrated by factor analysis and trials of convergent and divergent validity (Chren *et al.*, 1996; Chren *et al.*, 1997a, 1997b): factor analysis identifying 3 *a priori* scales. Its reduction to 29 items from 61 might have jeopardised content validity but Chren *et al.* (1997b) found that Skindex-29 showed increased utility. Moreover, Chren, Lasek, Sahay & Sands (2001) recently demonstrated the measurement properties of Skindex-16, a briefer QoL measure, while de Korte *et al.* (2002) found it to be the most valuable dermatology questionnaire for psoriasis research, based on internal structure, reliability and validity criteria.

### **6.3 Dermatology QoL Scales (DQLS: Morgan, McCreedy, Simpson & Hay, 1997)**

The 29-item DQLS measures the psychosocial impact of skin conditions by 4 scales of embarrassment, despair, irritableness and distress, suggesting it may be more useful to clinical psychologists. The DQLS has been shown to have high internal consistency (0.83-0.92) (Morgan *et al.*, 1997) and test-retest correlation of 0.84 over 7-10 days (Ashcroft, McCreedy, Simpson, & Hay, 1999). In terms of construct validity, it discriminated between dermatological populations when cross-validated against the

Nottingham Health Profile (NHP: Hunter, Savin, & Dahl, 1989) and demonstrated greater sensitivity to acne and psoriasis patients' experiences than to those of individuals with other conditions, although the extent of the correlation was not specified (de Tiedra *et al.*, 1998). However, its responsiveness remains untested (de Tiedra *et al.*, 1998) and its length may compromise clinical utility in dermatology and psychology settings.

#### **6.4 Dermatology-Specific QoL (DSQL: Anderson & Rajagopalan, 1997)**

The DSQL comprises 43 contact dermatitis-specific and 44 acne-specific items, which render it a semi-dermatology-specific scale. It focuses on QoL and contains 9 SF-36 items assessing emotional welfare. Anderson & Rajagopalan, (1997) demonstrated internal consistency (0.70 to 0.95), test-retest reliability (0.81 to 0.89) and external criterion validity (0.38 to 0.67) with patients' global distress scores, though they did not specify what this included. DSQL scores correlated with patients' perceived seriousness of their skin condition, indicating its psychological relevance and showed discriminative validity between patients with severe and less severe symptomology. Although de Tiedra *et al.* (1998) found it had only moderate responsiveness (0.25 to 0.29); Anderson & Rajagopalan demonstrated its sensitivity to clinical improvement in acne in a double

blind, placebo-controlled trial, albeit a lengthy assessment tool. Factor analysis indicated that the content of the DSQL was well characterised by the scales, although transposing items from the SF-36 into another context, in this case health-related to disease-specific QoL, may have compromised construct validity, as stand-alone items cannot be considered valid.

#### **6.5 Impact of Skin Diseases Scale (IMPACT: Wessley & Lewis, 1989)**

The 8-item Impact of Skin Diseases Scale also assesses the psychosocial effects of skin disease, including embarrassment about appearance. It is available in computer format and this speed of application may increase its clinical utility within a busy psychology clinic. The literature did not offer data on the validity or reliability IMPACT, or of its responsiveness to change, although de Tiedra *et al.* (1998) emphasised its lack of theory, stating that it had no psychological construct; it served simply to record behavioural change. Like the above scales, no independent data were available to support its validation.

#### **6.6 The Stigma Scale (Neil, 2000)**

The Stigma Scale (Neil, 2000) was developed using psychological theory and is the only dermatology-specific scale underpinned by the theoretical concept of body image (Benrud-Larson *et al.*, 2003), that poor body image in relation to the skin can be a result of experiences of enacted stigma. Factor analysis revealed 2 factors of “Stigma” with 11 items and “Psychosocial Factors” with 9 items, although the absence of independent studies means that it is unclear how these concepts are differentiated.

#### **6.7 Questionnaire on Experience with Skin Complaints (QES: Schmid, Jager, Kuensebeck, Ott & Lamprecht, 1996)**

Like the scale above, the QES, based on the Questionnaire on Experience with Skin Complaints (Ginsburg & Link, 1989) assesses skin distress from the psychological perspective of stigma. Construct validity was demonstrated by factor analysis, identifying five factors of self-esteem, retreat, rejection, composure and concealment and the QESC discriminated between subgroups with different affected regions (Schmid *et al.*, 1999).

### **6.8 Adjustment to Chronic Skin Diseases Questionnaire (ACSDQ: Stangier, Ehlers, & Gieler, 1998)**

The Adjustment to Chronic Skin Diseases Questionnaire was based on the psychological concept of self-regulation (Leventhal, 1970; Leventhal & Nerenz, 1983; Maes, Leventhal & de Ridder, 1996), positing that dermatological distress may be mediated by negative social reactions and the psychological threat of skin disease to body image and self-esteem, leading patients to experience reduced personal attractiveness (Ginsburg, 1995; Koo, 1995) and disfigurement (Jowett & Ryan, 1985).

### **6.9 The Leisure Scale (Ryan, 1991)**

The Leisure scale is a behavioural measure of the impact of skin conditions on leisure and social time. No independent validation data are available currently.

### **6.10 Coping with Chronic Skin Conditions (CSD: Niemeier, Ehlers, & Gieler, 2002)**

The use scale of this scale has been limited to the study of psychological factors associated with hand dermatoses, in which it showed discriminative validity between patients with high and low subjective reactions to stress. However, this narrow application limits its clinical generalisability.

Thus far, this review has suggested that most dermatology-specific scales approach psychodermatological assessment from a broadly psychosocial perspective that includes psychological concepts such as embarrassment, but, though a handful are grounded in psychological theory, evidence of construct validity is poor. Table 1 below highlights variability in their psychometric robustness. It illustrates that, although many scales are internally and temporally reliable, independent validation of criterion validity, especially across cultures, is limited largely to the DLQI. Table 1 reveals a striking dearth of evidence for face validity and little construct validation, even for the DLQI. It is this lack of theoretical robustness that will be examined later in relation to psychological theory. Some scales have clinical utility in assessing symptoms and are sensitive to treatment effects, although few have evidence of generalisability. It is arguable that disease-specific measures, that assess one skin condition only, provide a more sensitive assessment of skin-related distress than generic, dermatology-specific scales because they respond to the particular impact of different conditions (Finlay,

1997). This argument will be examined below in the evaluation of disease-specific scales.

#### **6.11 Table 1: Validities, reliability and sensitivity of dermatology-specific scales**

Criterion	Internal reliability	Temporal reliability	Content validity	Construct validity	External Criterion validity	Face validity	Cross-cultural validity	Sensitivity	Generalisability
<b>Scale</b>									
<b>DLQI (Finlay &amp; Khan, 1994)</b>	Badia <i>et al.</i> (1999) Finlay & Khan (1994) Shikiar <i>et al.</i> (2003) Zachariae <i>et al.</i> (2000)	Badia <i>et al.</i> (1999) Finlay & Khan (1994) Hahn <i>et al.</i> (2000) Reilly <i>et al.</i> (2003) Zachariae <i>et al.</i> (2000)	Hahn <i>et al.</i> (2000) Reilly <i>et al.</i> (2003)	Hongbo <i>et al.</i> (2003a)	Badia <i>et al.</i> (1999) Blackford <i>et al.</i> (1997) Clark <i>et al.</i> (1997) Finlay <i>et al.</i> (1990) Finlay & Khan (1994) Hahn <i>et al.</i> (2000) Herd <i>et al.</i> (1997) Jayaprakasam <i>et al.</i> (2002) Kent & Al-Abadie (1996) Linnet & Jemec (1999) Loo <i>et al.</i> (2003) Lundberg <i>et al.</i> (1999) Lundberg <i>et al.</i> (2000) Mallon <i>et al.</i> (1999) Newton <i>et al.</i> (1997) Newton <i>et al.</i> (1997) Nichol <i>et al.</i> (1996) Shikiar <i>et al.</i> (2003) Reilly <i>et al.</i> (2003) Ruta <i>et al.</i> (1998) Zachariae <i>et al.</i> (2000)	Harlow <i>et al.</i> (2000) Reilly <i>et al.</i> (2003)	de Tiedra <i>et al.</i> (1998) Loo <i>et al.</i> (2003) Nichol <i>et al.</i> (1996)	Badia <i>et al.</i> (1999) Clark <i>et al.</i> (1997) Klassen <i>et al.</i> (2000) Kurwa & Finlay (1995) Newton <i>et al.</i> (1997) Reilly <i>et al.</i> (2003) Shikiar <i>et al.</i> (2003) Touw <i>et al.</i> (2001)	Blackford <i>et al.</i> (1995) Blackford <i>et al.</i> (1996) Finlay (1987) Finlay & Khan (1994) Harris <i>et al.</i> (1996) Herd <i>et al.</i> (1997) Mallon <i>et al.</i> (1995) Newton <i>et al.</i> (1997)
<b>DSQL (Anderson &amp; Rajagopalan, 1997)</b>	Anderson & Rajagopalan (1997)	Anderson & Rajagopalan (1998)		Anderson & Rajagopalan (1997)	Anderson & Rajagopalan (1997) Rajagopalan & Anderson (1997)			Rajagopalan & Anderson (1997)	Anderson & Rajagopalan (1997)
<b>DQOLS (Morgan <i>et al.</i>, 1997)</b>	Morgan <i>et al.</i> (1997)	Morgan <i>et al.</i> (1997)							Morgan <i>et al.</i> (1997)
<b>IMPACT (Wessley &amp; Lewis, 1989)</b>					Wessley & Lewis, (1989)				
<b>Skindex-29 (Chren <i>et al.</i>, 1997)</b>	Chren <i>et al.</i> (1997)	Chren <i>et al.</i> (1997a, 1997b)	Chren <i>et al.</i> (1997)	Chren <i>et al.</i> (1997a, 1997b)				Chren <i>et al.</i> (1997) De Korte <i>et al.</i> , (2002)	
<b>Stigma Scale (Neil, 2000)</b>		Neil (2000)	Neil (2000)						
<b>Leisure Questionnaire (Ryan, 1991)</b>									
<b>ACS (Stangier <i>et al.</i>, 1998)</b>	Stangier <i>et al.</i> (1998)	Stangier <i>et al.</i> (1998)		Stangier <i>et al.</i> (1998)	Stangier <i>et al.</i> (1998)			Stangier <i>et al.</i> (1998)	
<b>QES (Schmid <i>et al.</i>, 1996)</b>	Schmid <i>et al.</i> (1996)				Schmid <i>et al.</i> (1996)				
<b>CSD (Niemeier <i>et al.</i>, 2002)</b>					Niemeier <i>et al.</i> (2002)				



## 7 DISEASE-SPECIFIC SCALES

Although they are clustered around psoriasis and acne, disease-specific psychodermatological measures of psoriasis, acne, dermatitis, eczema and melasma exist. They are sensitive to the particular effects of skin conditions but their specificity implies low generalisability and they cannot be used to compare dermatological populations (Klassen *et al.*, 2000). Joplin's (1976) questionnaire study established the experience of psoriasis sufferers as the most widely researched area of disease-specific measurement. McKenna and Stern's (1996) summary of the status of psoriasis measures drew attention to QoL approaches, concluding that the further development of psoriasis measures was necessary to assess functioning and well-being, while de Korte *et al.*'s (2002) review of the suitability of questionnaires for psoriasis research demonstrated that data on psoriasis-specific scales were relatively sparse. Psoriasis scales have assessed psoriasis from the perspectives of disability and stress, in addition to QoL. These scales are evaluated by disease category below.

### 7.1 Psoriasis

The well-established 23-item Psoriasis Disability Index (Finlay & Kelly, 1987) has been found through empirical study to be more representative of the impact of psoriasis on

patients' lives than the UK Sickness Impact Profile (UK-SIP, Bergner, Bobbitt, Carter & Gilson, 1981; Finlay *et al.*, 1990; Poyner & Menday, 1998) and sensitive to the effects of inpatient treatment (Finlay & Kelly, 1987). Kirby, Richards, Woo, Hindle, Main, & Griffiths (2001) showed that inpatients had significantly higher PDI scores than outpatients and higher depression scores on the Hospital Anxiety and Depression Scale (HADS: Zigmond & Snaith, 1983), demonstrating both discriminative validity and external criterion validity with the HADS (Lewis & Wessley, 1990). Finlay, Corvest, Lefrancois, & Taieb, (2001) adjudged the PDI valid, sensitive and specific through its administration within a French patient support group while a Spanish sample has shown some evidence of trans-cultural validity. A 15-item version is also available to enhance clinical utility. However, Kent & Al-Abadie's (1993) findings that some PDI items were applicable to patients with eczema and other skin diseases challenged its specificity to psoriasis. It correlated moderately with disease severity scores (Finlay *et al.*, 1990), though it is unclear whether or not this constitutes evidence of construct validity, as will be discussed later.

Five alternative psoriasis-specific measures exist. The Salford Psoriasis Index (SPI: Kirby, Corvest, Lefrancois, & Taieb, 2000) has been reduced from 41 to 15 items, enhancing clinical utility. Its "psychosocial disability" score has been shown to

correlate with the PDI, indicating external criterion validity (Kirby *et al.*, 2001). Unlike the PDI, the SPI has demonstrated no correlation between disease severity and psychosocial functioning (Kirby *et al.*, 2001).

The Psoriasis Life Stress Inventory (Gupta *et al.*, 1993) provides an index of psoriasis-related daily stress and does not correlate with disease severity (Fortune *et al.*, 1997a, 1997c), a finding that does not necessarily negate construct validity. It has demonstrated specificity, showing that stress resulting from other's reactions contributed more to the variance in patient's disability in everyday life than any other medical or health status variable. Like the PDI it showed external criterion validity, lower scores on all PLSI subscales relating to good psychological health on the SF-36 mental health dimension, and is available in a 15-item version (Gupta & Gupta, 1995).

The originators of the 25-item Psoriasis QoL instrument (McKenna *et al.*, 2003) have demonstrated promising psychometric robustness, including temporal stability ( $r = 0.89$ ), higher specificity than the DLQI in psoriasis, and discriminative validity in terms of perceived disease severity. Though its sensitivity to clinical change remains untested, it was tested explicitly for face validity in field-test interviews and problematic items rejected according to systematic analysis of respondents' feedback.

Finlay's (1997) paper offered a limited description of the Psoriasis Stressor Scale (Fleischer, Feldman, & Reboussin, 1994). It has relatively little psychological content, focusing on the assessment of disease severity. To conclude psoriasis measures, Ginsberg and Link (1989) devised the Stigmatisation in Psoriasis Questionnaire to further their fieldwork into the effects of this disease. However, it does not appear in routine clinical usage.

## **7.2 Acne**

Salek, Khan & Finlay's (1996) critique of questionnaire techniques in assessing acne handicap illustrated development in this area. In terms of psychometric robustness, the Cardiff Acne Disability Index (CADI: Motley & Finlay, 1989) and the 5-item Acne Disability Index showed good reliability and validity, and that the ADI (Motley & Finlay, 1992) was more specific to acne than the UKSIP. Salek *et al.* demonstrated test-retest reliability in the ADI and CADI, in addition to internal consistency and discriminative validity against a control group of fifty non-patients and concurrent validity with the UK-SIP. An independent Australian study by Oakley (1996) confirmed the usefulness of the ADI: Oakley reported the same median pre-treatment ADI of 6

(range 2-14) as the original study, indicating cross-cultural validity. The forthcoming French version of the CADI might improve its cross-cultural validity (Finlay, Dreno, Nocera, Verriere, Myon *et al.*, 2003). Finlay (1998) described the CADI as “too unwieldy for routine clinical use”, though it could be argued that the ADI, though more clinically useful, may lack content validity.

Whilst the CADI correlates with bodily acne severity, the 15-item Assessment of the Psychological and Social Effects of Acne (Layton, Eady & Cunliffe, 1991), which includes 6 items from the HADS, correlates with facial but not total acne severity (Clark *et al.*, 1997; Layton, 1994). This suggests that both scales require further evidence of construct validity in order to ascertain exactly which effects of acne they measure. Furthermore, the 3 APSEA items that have shown temporal reliability and criterion validity within the HADS may be neither reliable nor valid within the APSEA.

Finally, the 19-item Acne-QoL (Martin, Lookingbill, Botek, Light, Thiboutot, *et al.*, 2001) consists of self-perception, role-social and role-emotional domains, has high internal consistency, good temporal stability and was responsive to changes following isotretinoin treatment, although discriminative validity could not be demonstrated, due to the unblinded, nonrandomized nature of the treatment groups.

### 7.3 Miscellaneous Scales

As the Eczema Disability Index is adapted from the PDI (Finlay, 1997), it may lack sensitivity to eczema and dermatitis patients. The Quality of Life in Atopic Dermatitis (Whalley, McKenna, Dewar, 2000) was developed internationally but has not been validated independently. The 10-item Melasma-QOL (Balkrishnan *et al.*, 2003) assesses QoL impairment in melasma. Like the EDI, MELASQOL borrowed items from an established scale, this time Skindex-16 (Chren *et al.*, 2001), combining them with 3 discolouration items. MELASQOL showed discriminative validity between women with emotional and psychological problems and others, and external criterion validity with Skindex-16 and the DLQI.

To summarise, disease-specific scales, like dermatology-specific scales, rely on quantitative methodology, although there is less evidence for the psychometric robustness of disease-specific scales than the dermatology-specific category. Acne-related scales are especially weak in terms of temporal reliability, though arguably more clinically useful than dermatology-specific scales due to their generally shorter length. The miscellaneous group are particularly poorly validated. Like the dermatology-

specific group, there is a dearth of construct validation and surprisingly little evidence of content validity, given the scales' greater specificity. Apart from the PDI, their sensitivity is largely untested. Validation studies of a French CADI to improve cross-cultural validity are ongoing (Finlay *et al.*, 2003), although items relating to concepts such as disability and stress might be culturally determined and therefore not readily generalisable to other populations (Papadopoulos & Bor, 1999).

#### **7.4 Summary of psychometric robustness**

This examination has illustrated that there are fewer validation studies in the disease-specific category than for dermatology-specific scales and less evidence of internal and temporal reliability. Overall, there is very little evidence of internal or face validity, and critically, of theoretical robustness. The DLQI and PDI are the best independently validated scales, though evidence is growing for the ADI, CADI and Skindex. However, the limited evidence of psychometric robustness does not guarantee that psychodermatological scales are meaningful to individuals with skin conditions, or that they contribute to the understanding of skin distress. Having evaluated both categories of scales according to psychometric criteria, common theoretical and methodological concerns emerging from the literature will be discussed.

## **8 DISCUSSION**

### **8.1 Theoretical Concerns**

#### **8.1.1 A-theoretical Scale Development**

Thus far, this review has demonstrated that most psychodermatological scales were developed as research and clinical outcome measures, rather than to contribute to the understanding of skin distress. The literature reviewed has confirmed that the “scant regard for theory” observed in most dermatological investigations by Kellett & Gawcroger (1999) has been reflected in psychodermatological scale development. Psychodermatological assessment has become dominated by quantitative self-report QoL questionnaires. Ashcroft *et al.* (1999) described QoL as “a multidimensional concept encompassing the physical, social and emotional well-being of a person”, relating to their disease process and treatment. Health-related QoL measurement has been a useful framework around which to organise psychodermatological assessment but has given rise to pragmatic, rather than theoretical scale development, as QoL is a composite approach, rather than a unified psychological theory. Anderson & Rajagopalan (1998) commented that most scales did not resemble the conceptual model



of QoL adapted by research scientists, while McKenna *et al.* (2003) argued that dermatology and psoriasis-specific instruments such as the PDI, DLQI, PLSI, Skindex-29 and DQLS focus on symptoms and functioning, rather than on a comprehensive assessment of the impact of disease.

For this reason, most psychodermatological scales can be said to have been developed a-theoretically, although a limited number are more theory driven. The Stigma Scale, QESC and ACSDQ provide a more psychological assessment of dermatological distress because they were developed from the established psychological concepts of stigma and body image. The recently developed PSORIQoL, MELASQOL and Acne-QoL have greater psychological face-validity, perhaps indicating a shift towards a greater emphasis on psychological theory. However, many of the scales reviewed (DLQI, Skindex-29, DQLS, DSQL) are limited to assessing symptoms of emotional distress.

Instead, many psychodermatological scales favour the social dimension of biopsychosocial assessment, illustrating the impact of skin diseases on relationships (APSEA, ADI, MELASQOL, DLQI and PDI), while the PSI reflects psychosocial disability. Kent & Al-Abadie's (1996) factor analysis of the PDI demonstrated a two-factor structure: one relating to the effects of psoriasis on daily living activities and the

other concerning public situations in which patients might be criticized, the latter of which could be conceptualised as social anxiety, in contrast to the a-theoretical “common-sense” grouping of items suggested by Finlay & Kelly (1987). Despite such evidence, it is striking that de Tiedra *et al.* 's (1998) selection of an instrument for cross-cultural adaptation included no consideration of existing scales' theoretical qualities, indicating that this has not been valued.

### **8.1.2 Item Generation**

The absence of theory has been reflected in item generation. Most scales were developed from qualitative reports by patients and clinicians, or “generation methodology” (Wackerbarth, Streams, & Smith, 2002), which has the advantage of conferring ecological and face validity. For example, DLQI items were based on the responses of 120 patients about the impact of their condition and the QES on Ginsburg & Link's fieldwork (1989). The DLQI combines symptoms and feelings into one scale though these are distinct concepts and their relationship is unclear. Items in disease-specific scales have been similarly data driven. Finlay & Kelly (1987) devised PDI items by studying 54 patients with psoriasis, determining the 10 most relevant and independent questions according to an overall disability score (McKenna & Stern,

1996). Motley & Finlay (1992) selected the 5 ADI questions from qualitative studies (Motley & Finlay, 1989) and the PLSI was based primarily on its authors' clinical experience (Gupta & Gupta, 1995). The absence of conceptual grounding of items undermines scales' construct validity because what they purport to measure is unclear. For example, Kirby *et al.* (2000) did not clarify the origin of the SPI "Psychosocial Impact Score", and Finlay (1997) did not detail the origin of the APSEA's "psychological" questions. The incorporation of items from other scales (DSQL, APSEA and MELASQOL) reflects this a-theoretical approach.

Generation methodology has distinct advantages in affording the scales' ecological and content validity and clinical utility. However, it risks the omission of crucial items that may not be relevant to the study sample and therefore, not identified (Wackerbarth *et al.*, 2002). It also has theoretical limitations in terms of understanding skin distress because a-theoretical items cannot be used to explain how symptoms, emotions and psychological perceptions might be linked, which contributes to the scales' limited construct validity. Though this approach should improve face and content validity, few studies have demonstrated this to date.

### **8.1.3 Psychological Assessment**

Their emphasis on health-related QoL and a-theoretical approach mean that current scales provide only limited psychological assessment of skin distress. Psychological aspects of disease are considered as only one aspect of QoL assessment, which is reflected in the paucity of psychological scale items. Balkrishnan *et al.* (2003) argued that the DLQI and Skindex-29 assess QoL by equally weighting physical and psychological distress. However, as the DLQI contains only one item relating to emotional well-being, its ability to assess skin distress psychologically may be overstated. Hongbo *et al.* (2003a, 2003b) concluded that it had content validity in terms of health-related QoL, rather than psychodermatological distress. Skindex-29 was based on a model of disability (Chren *et al.*, 1997a), rather than on a psychological theory of skin distress. Thus, it is doubtful whether even more established psychodermatological scales provide meaningful psychological assessment. The widespread usage of generic psychological scales alongside them exemplifies this (de Korte *et al.*, 2002).

### **8.1.4 Theory-Practice Links**

This critique does not imply that existing scales are clinically worthless. Many individuals with skin conditions undoubtedly experience significant QoL impairment. However, research has suggested that it is the psychological aspects of QoL that are most salient to people with skin conditions. Kent & Al-Abadie (1996) found the DLQI to correlate more strongly with self-esteem and perceived stigma than with severity, underlining the salience of psychological factors. Balkrishnan *et al.* (2003) found that the QoL domains most affected included emotional well-being, which correlated with QoL impairment, while Salek *et al.* (1996) discovered that ADI psychological factors correlated most strongly with overall disability, and were the most salient factor differentiating the experiences of acne sufferers and non-sufferers. An association has also been shown between perceived disability and self-reported losses in psychological functioning (Finlay *et al.*, 1990, O'Neill & Kelly, 1996). However, despite this compelling evidence, existing scales do not reflect these psychological correlates.

Not only may existing scales fail to reflect psychodermatological distress fully, their lack of theory means that they offer little understanding as to why some individuals with skin conditions experience psychological distress and others do not. Fortune, Main, O'Sullivan, & Griffiths, (1997a, 1997b) reported that research into the effects of psoriasis on patients' functioning has been concerned with the unitary assessment of psychological adjustment to the condition, suggesting that adjustment is one mediator of

the distress associated with skin disease. Biopsychosocial models of skin distress (Gupta & Gupta, 1995; Fleischer *et al.*, 1994, Fleischer, Feldman, Rapp, Reboussin, & Eun, 1996; Kellett & Gilbert, 2001) have suggested that individuals who experience stress from coping with the effects of skin disease are more at risk in terms of their mental health. However, current scales provide no evidence about the mediators of skin distress or the specific direction of effects. The scales reviewed do not, therefore, offer the thorough psychodermatological assessment indicated by research into skin distress. They also have methodological weaknesses that affect their psychological value, as will be discussed next.

## **8.2 Methodological Weaknesses**

This section addresses methodological themes emerging from the literature regarding psychodermatological assessment. These include design, measurement issues, multiple testing and common method variance.

### **8.2.1 Design**

Psychodermatological assessment relies on quantitative assumptions, using subjective assessment in questionnaire format. This approach has advantages; people with skin

disease can collaborate in assessment and rate the impact of their condition according to their perceptions. This is useful in psychological terms as self-perceptions play a crucial role in the development of skin distress (Gupta & Gupta, 1995, 1998; Kellett & Gawkröger, 1999; Koo, 1995, 2000; Martin *et al.*, 2001) as do the meanings individuals attach to skin conditions (Papadopoulos *et al.*, 1999). Self-report methodology seems to provide more accurate assessment as dermatologists tend to under-rate psychodermatological distress: studies have consistently shown low levels of association between subjective (i.e. patient) and objective (i.e. dermatologist) assessment (Jayaprakasam *et al.*, 2002; McKenna *et al.*, 2003), though this may also indicate the inflation on symptoms on the part of the patient.

However, though there is no evidence that the self-report approach of these scales has adversely affected their reliability, psychodermatological instruments have been criticised for being over-reliant on subjective parameters (Sugarman, McCalmont, Frieden, Dover, & Arndt, 2003). The studies that have found patients' severity scores to be consistently higher than those of the dermatologist (Kellett & Gawkröger, 1999; McKenna & Stern, 1996) may reflect scales' validity. The subsequent shift towards the objective measurement of skin conditions may be valid in methodological terms but

subjective distress may be more salient to the biopsychosocial understanding of skin conditions and the development of interventions.

Despite the contribution of qualitative studies to the understanding of psychodermatological distress (Ginsburg & Link, 1989; Ryan, 1991), no validated qualitative assessment of dermatological distress has been developed, for example, in the form of a structured clinical interview. This may be because psychodermatological scale development has been driven by dermatologists, whose objective was clinical utility and generalisability, but means that patients' subjective experiences were less salient.

### **8.2.2 Measurement**

Other methodological weaknesses concern measurement. Most scales rely on point prevalence data; some over the last week (DLQI) and others the last month (APSEA), so they cannot always be compared directly. They also utilize retrospective reports, which may limit accuracy and conflate dispositional and situational responses. There is evidence that distress arising from skin disfigurement changes over time (Kent, 2000; Thompson, 1998) according to the individual's mood, life events and environment, and skin flare-ups can change self-perceptions dramatically. Thus, scales do not reflect the



changing nature of distress, sometimes giving a misleading picture of individuals' well-being. Like symptom scales, they can provide an idea of the extent or degree of skin disease, offering the assessor a snapshot of the patient's experience. As the concept of QoL is multidimensional (de Tiedra *et al.*, 1998), these scales provide information about symptoms, functioning, disability and psychosocial factors, critical to biopsychosocial assessment. However, this breadth of coverage compromises the scales' psychological specificity.

Additionally, some scales were developed without adequate comparison groups, for example the DQLS and DSQL, resulting in no normative data being available. Others, like the Stigma Scale used student samples, which significantly undermines its validity within clinical populations. De Tiedra *et al.* (1998) commented that, without needing to achieve the highest standard, psychodermatological scales should have shown an acceptable level of development. While this criterion has been met by some of the scales reviewed, for example the DLQI, Skindex-29 and PDI, it is perhaps symptomatic of underdevelopment in this area that the highest standards have neither been demanded nor met.

### **8.2.3 Multiple Testing**

The DLQI demonstrates greater reliability, validity and sensitivity than other dermatology-specific scales because it is the only one to have undergone continuous testing, much of which is independent of the originators. Many instruments, like the IMPACT and APSEA have been sparsely tested (Anderson & Rajagopalan, 1998).

### **8.2.4 Common Method Variance**

As the DLQI is well validated, many scales are validated against it (Clark *et al.*, 1997; Herd *et al.*, 1997; McKenna *et al.*, 2003; Reilly *et al.*, 2003). Skindex-29 has also been used as a criterion scale (Balkrishnan *et al.*, 2003), while psoriasis and acne-specific scales have often been used together within the same study (Clark *et al.*, 1997; Fortune *et al.*, 1997a, 1997b; Kirby *et al.*, 2000, 2001; Salek *et al.*, 1996). As the ADI was abbreviated from the CADI, both scales were highly correlated, while the MELASQOL has a similar relationship with Skindex-29. However, rather than providing evidence of external criterion validity, this method means that data may be flawed by statistical artefacts, such as common method variance. The proposed validity of many scales may

simply reflect either the measurement of the same underlying mechanism or over-reliance on a single source of data.

## **9 CRITICAL THEMES**

In addition to methodological and theoretical issues, the literature revealed a number of consistent themes concerning skin distress and its relationship with disease severity that will be expanded on below.

### **9.1 Desynchrony**

Papers on psychodermatological scale development suggest desynchrony - a weak, non-existent, or negative correlation between skin disease severity, especially when reported by dermatologists, and distress. This makes the evaluation of scales' construct validity an issue, due to debate regarding whether or not correlation between a scale and severity is evidence of validity (Jayaprakasam *et al.*, 2002; Jemec & Wulf, 1996; Koo, 1995).

Desynchrony will be examined below in relation to disease severity, disability and clinician report.

### 9.1.1 Desynchrony between disease severity and skin distress

Herd *et al.* (1997) claimed that disease severity was “the ideal measure for testing scales’ construct validity” but it is uncertain whether or not it is predictive of psychological distress (Clark *et al.*, 1997; Finlay, 1997). Some DLQI studies have shown correlations of up to 0.79 with the patient-reported Psoriasis Symptom Assessment Scale in outpatients (Jayaprakasam *et al.*, 2002; Lundberg *et al.*, 1999), while CADI (Salek *et al.*, 1996) and Acne-QoL (Martin *et al.*, 2001) scores also revealed a trend of worsening scores with increasing severity

However, the majority of evidence suggested weaker correlations. Changes in DLQI scores were only moderately correlated with changes in self-reported psoriasis severity (Mazzotti *et al.*, 2003; Touw *et al.*, 2001), while the correlation of  $r = 0.51$  between severity scores and psychological disability on the PDI and SPI suggested that for some patients, there was only moderate correlation (Kirby *et al.*, 2001). Other studies found no relationship between Skindex-29 and severity (Chren *et al.*, 1997a, 1997b), DLQI scores and the extent of vitiligo (Papadopoulos *et al.*, 1999), DLQI and acne severity (Mallon *et al.*, 1999) and MELASQOL and severity (Balkrishnan *et al.*, 2003). It seems

therefore, that either there is only a slight relationship between severity and distress, or current scales are insensitive to the impact of severity on psychological well-being. Though QoL scales are one method of determining psoriasis severity, the evidence of subjective distress means that a psychological assessment tool might be equally valid. Balkrishnan *et al.*'s starting point when developing the MELASQOL was that melasma had a distinctly greater impact on psychosocial rather than physical aspects of a patient's life; an indication perhaps of a shift towards a greater recognition of psychological factors.

### **9.1.2 Desynchrony between self and clinician report**

The provenance of assessment is, however, salient. Studies consistently show little association between objective and subjective disease measurement (McKenna *et al.*, 2003) and patients' scores correlate better with changes in treatment status (Balkrishnan *et al.*, 2003). Shikhar *et al.*'s (2003) study suggested that patient and dermatologist-reported assessment were significantly closer at the end of the study than at baseline, from  $r = 0.19$  to  $0.53$ , although it is unclear how this occurred. This convergence of clinicians' scores with self-report data suggests that existing scales' reliance on self-report methodology may enhance their construct validity. A number of explanations

have been posited for this lack of relationship between disease severity and subjective distress<sup>3</sup>.

## 10 CONCLUSION

In summary, this review has demonstrated the significant relationship of skin disease with distress and the subsequent need for biopsychosocial assessment. It has identified that this has been addressed by the development of dermatology and disease-specific self-report questionnaires. However, it has also shown that though most existing psychodermatological scales have limited clinical utility, they are restricted to assessing QoL impairment or disability and offer limited psychological assessment. Whilst it is likely that health-related QoL impairment exists for individuals with skin disease, this

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<sup>3</sup> Severity may not predict distress because adapting to minor blemishes may be less problematic than major disfigurement, as the affected individual becomes habituated to revealing their skin. Dermatologists have suggested that others may react more sympathetically to severe disease; thereby moderating any distress the individual may feel (G. Sobey, personal communication, 16<sup>th</sup> December, 2003). It is likely that desynchrony arises because severity ratings and psychodermatological scales measure different concepts: the former measuring the objective extent of disease, and the latter the subjective experience of illness. Fortune, Richards, Griffiths & Main (2002) proposed that studies in a range of conditions have suggested that the clinical severity of a patient's condition is a poor indicator of subsequent downturns in QoL or psychological well-being. The notion of a linear relationship between disease severity or illness and psychological variables is unlikely to be correct as it implies passivity on the patient's part and denies the conceptual difference between *disease* (objective pathology), and *illness* (the subjective experience of changes in well-being).

approach lacks a theoretically coherent psychological basis, reflected in the diversity of interpretations of QoL. This inevitably leads to variability in the way that skin distress is measured and means that scales have not been utilized to develop the biopsychosocial model of skin distress.

The literature did not reveal psychologically grounded, theoretically robust measures of dermatological distress. Psychometric evaluation showed that most scales, especially dermatology-specific instruments, have limited reliability and validity, while theoretical examination suggested that they have some applicability to the psychosocial assessment of skin diseases. However, though psychological distress is related to, and one component of QoL impairment, it remains a distinct domain. As psychological factors tend to feature as only one component of psychodermatological scales, rather than providing theoretical focus, the underpinnings of psychological items are critically unclear and subscales have no validity. Key aspects of maladjustment to skin disease, such as perceptions of stigma and shame reactions, are uniquely psychological, with the QoL concept being a poor conceptual umbrella for individuals' subjective experiences of skin distress. Subsequently, the criterion variables of many scales may not assess adequately the experiences and behaviours reported by individuals with skin conditions, such as avoidance and concealment. This means that individuals' experiences are not

being accurately portrayed and understood. In short, the scales reviewed have not identified the biopsychosocial processes that mediate skin distress and are of limited clinical use to psychologists.

The other conclusion that can be drawn is that further psychodermatological scale development is required. Future scales should improve on those reviewed here by employing sound theoretical development and independent validation, to further inform the biopsychosocial model of psychodermatological distress. They should be developed with a dermatological population to maximize validity. A clinician-reported measure of psychological distress in skin conditions, or a scale designed for significant others might provide external triangulation. In short, psychodermatological assessment appears on the whole a field that is in its theoretical and methodological infancy but one that shows worrying abandon in terms of crucial concepts.



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**APPENDIX 1: LETTER OF APPROVAL FROM THE CHAIR OF THE RESEARCH  
SUB-COMMITTEE, THE UNIVERSITY OF SHEFFIELD**



# THE UNIVERSITY OF SHEFFIELD

## Clinical Psychology Unit

### Department of Psychology

Doctor of Clinical Psychology (DClin Psy) Programmes (Pre-registration and post-qualification)  
Clinical supervision training and NHS research training and consultancy

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31st March 2004

Caroline Scott  
Third year trainee  
Clinical Psychology Unit  
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Dear Caroline

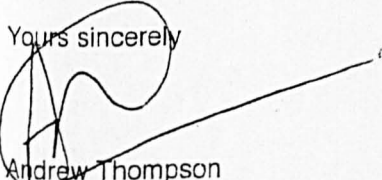
I am writing to indicate our approval of the journal(s) you have nominated for publishing work contained in your research thesis.

**Literature Review:** British Journal of Health Psychology

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Please remember to bind in this letter and copies of the relevant Instructions to Authors with your thesis.

Yours sincerely

  
Andrew Thompson  
Chair, Research Sub-Committee

**APPENDIX 2: GUIDELINES FOR AUTHORS, BRITISH JOURNAL OF HEALTH  
PSYCHOLOGY**

## Notes for contributors

The aim of the *British Journal of Health Psychology* is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology across the life span, ranging from experimental and clinical research on aetiology and the management of acute and chronic illness, responses to ill-health, screening and medical procedures, to research on health behaviour and psychological aspects of prevention. Research carried out at the individual, group and community levels is welcome, and submissions concerning clinical applications and interventions are particularly encouraged.

The following types of paper are invited:

- papers reporting original empirical investigations;
- theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations;
- review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology;
- methodological papers dealing with methodological issues of particular relevance to health psychology.

### Circulation

The circulation of the Journals is worldwide. Papers are invited and encouraged from authors throughout the world.

### Length

Pressure on Journal space is considerable and papers should be as short as is consistent with clear presentation of the subject matter. Papers should normally be no more than 5,000 words, although the Editor retains discretion to publish papers beyond this length.

### Refereeing

The journal operates a policy of anonymous peer review. Papers will normally be scrutinised and commented on by at least two independent expert referees (in addition to the Editor) although the Editor may access a paper at his or her discretion. The referees will not be made aware of the identity of the author. All information about authorship including personal acknowledgements and institutional affiliations should be confined to the title page (and the text should be free of such clues to identifiable self-citations ('In our earlier work...')).

### Submission requirements

- 1) All manuscripts must be submitted online via *Editorial Manager*® at [www.bpsjournals.co.uk](http://www.bpsjournals.co.uk). Submission of a paper implies it has not been published elsewhere and it is not being considered for publication in another journal.
- 2) Contributions must be typed in double spacing with wide margins and on only one side of each sheet. All sheets must be numbered.
- 3) Tables should be typed in double spacing, each on a separate piece of paper with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text.
- 4) Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate page. The resolution of digital images must be at least 300 dpi.
- 5) All articles should be preceded by an Abstract of between 100 and 200 words, giving a concise statement of the intention and results or conclusions of the article.
- 6) Bibliographic references in the text should quote the author's name and the date of publication thus: Smith (1994). Multiple citations should be given alphabetically rather than chronologically: (Jones, 1998; King, 1996; Parker, 1997). If a work

has two authors, cite both names in the text throughout. Page and White (1995). In the case of reference to three or more authors, use all names on the first mention and et al. thereafter except in the reference list.

- (g) References cited in the text must appear in the list at the end of the article in current APA style. The list should be typed in double spacing in the following format:  
Herbert, M. (1993). *Working with children and the Children Act* (pp. 76-106). Leicester: The British Psychological Society.  
Kanvil, N., & Umeh, K.F. (2000). Lung cancer and cigarette use: Cognitive factors, protection motivation and past behaviour. *British Journal of Health Psychology*, 5, 235-248.  
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**UNDERSTANDING PSYCHODERMATOLOGICAL DISTRESS:  
CONSTRUCTING A SKIN SHAME SCALE**

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WORD COUNT 7679

# UNDERSTANDING PSYCHODERMATOLOGICAL DISTRESS: CONSTRUCTING A SKIN SHAME SCALE

## 1 ABSTRACT

**Objective** Shame has been posited as a key emotion in adjustment to disfiguring conditions (Kellett, 2002; Kent & Thompson, 2001). This study aimed to construct a psychodermatological assessment scale measuring shame, called the Skin Shame Scale (SSS). Exploratory factor analysis was used to refine the scale and preliminary testing of its reliability and validity was undertaken.

**Design** A cross-sectional study using factor analysis to construct a questionnaire, and inferential statistics to test hypotheses.

**Method** Participants ( $n = 162$ ) referred to a dermatology outpatients' department completed the initial 30-item SSS, Hospital Anxiety and Depression Scale (HADS: Zigmond & Snaith, 1983), Internalized Shame Scale (ISS: Cook, 1994) and perceptual indices of disease severity.

**Results** Principal axis analysis reduced the SSS to 24 items, comprising of 4 factors. It was found to have satisfactory reliability, consistency and external validity, correlating highly with the HADS and ISS.

**Conclusion** This study contributes to the psychodermatological literature in developing a scale based on psychological theory with promising psychometric robustness. These findings have implications for the psychological understanding of skin distress. Methodological limitations are identified.

**Key words** psychodermatology, shame, disfigurement, exploratory factor analysis

## **2 INTRODUCTION**

### **2.1 Aim**

The central aim of this study was to develop a measure of psychological distress in skin conditions, based on the theory of dermatological shame.

### **2.2 Overview - the biopsychosocial model of skin-related distress**

The development of the scale reflected a biopsychosocial understanding of the impact of an individual's thoughts, emotions, motives and behaviour on their skin condition, and vice-versa (Root, Kent & Al'Abadie, 1994; Barankin & DeKoven, 2002; Fortune, Richards, Griffiths & Main, 2002a; Papadopoulos, Bor & Legg, 1999b). The biopsychosocial model of disease takes into account psychological and social, as well as physiological factors on the development and maintenance of skin diseases (Arruda & Moraes, 2001; Fortune, Main, O'Sullivan, & Griffiths, 1997; Fortune *et al.*, 2002a; Papadopoulos, Bor & Legg, 1999).

This model may help to explain why some people with skin conditions become distressed, whilst others do not. Some may ruminate on their condition, becoming depressed and anxious (Barankin & De Koven, 2002; Fortune & Main, 2002a; Gupta & Gupta, 2001b; Papadopoulos *et al.*, 1999; Richards, Fortune, Griffiths & Main, 2001), and struggling to live alongside their condition (Thompson, Kent & Smith, 2002). Linnet & Jemec (1999) and Lundberg, Johannesson, Silverdahl, Hermansson, & Lindberg, (2000) found that people with dermatitis had significantly lower life quality and higher state and trait anxiety than controls, even when allowing for individual differences, findings replicated by Rapp, Cottrell & Leary, (2001) in a sample of psoriasis patients. Skin conditions can generate dissatisfaction with body appearance (Gupta & Gupta, 2001a), shame and skin-related embarrassment (Kellett, 1996; Koblenzer, 1997), especially for patients with acne (Kellett & Gawkröger, 1999; Picardi, Abeni, Renzi, Braga, Melchi, *et al.*, 2003), which can lead to high psychiatric morbidity (Picardi, Abeni, Melchi, Puddu, & Pasquini, 2000), suicidal ideation (Gupta, Schørk, & Gupta, 1993; Picardi *et al.*, 2000), attempted and completed suicide (Cotterill & Cunliffe, 1997; Humphreys & Humphreys, 1998). Psychosocial factors have been recognized as important in 24-33% of dermatology patients (Gupta & Gupta, 2001b; Picardi *et al.*, 2000), while psychiatric morbidity has been estimated at between 8%

(Picardi *et al.*, 2003) and 24% (Hughes, Barraclough, Hamblin, & White, 1983; Picardi *et al.*, 2000, 2003; Woodruff, Djang, McLendon, Heinz, & Voorhees, 1997).

It seems, therefore, that living with a skin condition can cause significant psychological disturbance for some people. Papadopoulos, Bor & Legg (1999b) described the unique nature of the issues raised for people suffering from cutaneous illness, including adjusting to and accepting changing appearance, and arduous treatment regimes (Koblenzer, 1997). Such factors appear to be more influential than disease severity in the development of psychological distress.

### **2.3 The relationship between disease severity and distress**

Most psychodermatological studies concur that the amount of distress an individual suffers as a result of their skin disease depends less on its clinical severity, and more on the person's psychological interpretation of and adaptation to the disease itself. Numerous studies measuring dermatological quality of life have found discrepancies between disease severity and psychological functioning (Clark, Goulden, Finlay, & Cunliffe, 1997; Finlay *et al.*, 1990; Fortune *et al.*, 1997; Kellett & Gawkröger, 1999; Kirby *et al.*, 2000), although evidence to the contrary exists (Chren *et al.*, 1997).

Assessment of the psychometric properties of the Psoriasis Life Stress Inventory (Fortune, Lasek, Flocke & Zyzanski, 1997) confirmed that disease severity neither predicted nor correlated with stress, but that psoriasis patients could distinguish and process their symptoms and psychological reaction to them independently. Using the same scale, Kirby *et al.*, (2000) found no relationship between severity and psychosocial impact, whilst Carr, Harris & James (2000) implied that distress is determined by neither disease site nor extent, arguing that even apparently minor skin blemishes can generate significant distress for many people. Linnet & Jemec (1999) argued that emotional and mental health-related consequences of skin conditions should not be inferred from disease severity, but from their psychological impact and that the severity of a person's skin condition is a poor indicator of their psychological outcome.

Though there evidence exists that patients with widespread inflammatory disease are severely handicapped (Finlay, 2000), it seems that the psychological meaning or interpretation people make of disfiguring skin conditions affects their psychological reactions (Finlay & Dowling, 2000). Quality of life scores tend to correlate with patient, rather than physician-reported severity (Thomson, Wilkinson, Sommer, & Pollock, 2002), suggesting that patients' perceptions of their disease may be salient predictors of distress (Martin *et al.*, 2001; Motley & Finlay, 1992) and have been found to impact on

psychological adjustment and functional ability (Fortune *et al.*, 1997). The importance of perceptions in the experience of skin distress (Papadopoulos, Walker, Bor & Legg, 2001; Richards *et al.*, 2001) results in patients and dermatologists consistently rating the severity and impact of skin conditions differently (Sampogna, Picardi, Melchi, Pasquini, & Abeni, 2003).

Psychodermatological evidence has suggested that a number of demographic variables may also contribute to variance in sufferers' reactions: the impact of skin conditions may decrease and individuals' adjustment improve with age, a number of studies have found that skin diseases have a greater adverse effect on younger people (Fortune *et al.*, 1997; Ginsberg, 1995; Gupta & Gupta, 1995; Lundberg *et al.*, 2000; McKenna & Stern, 1997; Niemeier, Nippesen, Kupfer, Schill, & Gieler, 2002; Schmid, 1996; Zachariae, Zachariae, Ibsen, Mortensen, & Wulf, 2000). Whilst some evidence exists that older adults are increasingly being affected by acne (Lasek & Chren, 1998) or experience similar shame experiences (Harlow, Poyner, Finlay & Dykes, 2000) the weight of evidence suggests that older people adjust better to skin disease. Other studies have emphasised the greater impact of skin diseases on women than men in terms of symptoms and affective components (Kellett & Gawkröger, 1999; Gupta & Gupta, 2001b; Lundberg *et al.*, 2000; Picardi *et al.*, 2000; Richards *et al.*, 2001; Siegert &



Ward, 2002; Zachariae *et al.*, 2000). This may be explained in part by the greater dependency of women on social appearance and relationships, and has been attributed to greater social competition among women and objectification (Herberger, 2000; Resnick, 2000). Evidence for the impact of visibility is persuasive (Cotterill & Cunliffe, 1997; Papadopoulos, Walker, Aitken, & Bor, 2000).

Thus, factors such as age, gender and location have been shown to be moderately predictive of skin distress. However, there is growing evidence that personality factors may be more salient, and that the greatest of these may be shame (Kellett, 2002).

#### **2.4 Stigma, body shame and dermatological shame**

If disease severity has been shown to be unrelated to skin distress, the effects of stigmatization, and resulting shame, are better evidenced (Ginsberg & Link, 1989, 1993; Koblenzer, 1997; Lim & Tan, 1991; Rapp *et al.*, 2001; Richards *et al.*, 2001; Vardy, Besser, Amir, Gesthalter, Biton, *et al.*, 2002). Stigma has particular meaning and pertinence for patients with skin diseases (Kent, 2000), as its source is often visible and can lead to a high degree of social avoidance (Richards *et al.*, 2001; Wessley & Lewis, 1989).

The explanation for this may lie in perceptions, in this case, the interpretation and reactions of others, as well as how people perceive themselves. Papadopoulos *et al.* (1999b, 2001) suggested that body satisfaction is derived from a person's beliefs about how they are perceived by others. People develop internal cognitive representations of their condition and the nature and extent of its psychological impact develops from the meaning each individual attaches to their skin state, which may in turn affect their interpretations of the reactions of those around them. Cash (1990), Cash & Labarge, 1996 and Lansdown, Rumsey, Bradbury, Carr & Partridge *et al.* (1997) proposed that stigmatizing experiences play a role in generating cognitive schema that relate to appearance anxiety. Repeated stigmatizing experiences alter cognitive responses, sometimes leading to benign responses being perceived as hostile and mediating the association between disease severity and patients' distress (Vardy *et al.*, 2002). Resulting beliefs may set up a cycle whereby skin disease negatively affects psychosocial functioning (Papadopoulos, *et al.*, 1999a). Such cognitive mechanisms perpetuate body dissatisfaction and may lead to body shame.

So how might shame be relevant to skin conditions? The concept of shame is useful in explaining distress as it affects psychosocial development, which has a profound impact

on cognitions, emotions and behaviour (Gilbert, 1998). A number of theorists have attempted to conceptualise shame in relation to the body; Papadopoulos, Aitken, Bor & Legg, (2000) proposed an “intervening cognitive variable” which affects an individual’s representations of their illness, while a direct connection between shame and body image disturbance has been proposed (Benrud-Larson, Heinberg, Boling, Reed, & White, 2003; Gilmore, 2000). Andrews, Mingyi & Valentine (2002) suggested that body shame generates avoidance and concealment behaviour and ruminative preoccupation with others’ perceptions, in ways body dissatisfaction and negative self-evaluation do not. The social visibility of skin conditions means that a vulnerability to shame and shame reactions appears likely. Such shame reactions may be crucial to the experience of skin distress (Ginsburg & Link’s 1989; Jowett & Ryan 1985; Koblenzer, 1997): Jowett & Ryan reported that 80% of people with skin conditions described shame and embarrassment as its worst aspects, while Ginsburg & Link reported participants’ shame and embarrassment regarding their condition, reduced confidence and high incidence of depressive feelings regarding psoriasis. Andrews *et al.*’s (2002) suggested that shame plays a central role in the onset and course of depression for people with skin disease.

Shame has been defined as a multifaceted experience comprising social, self-evaluative, emotional, behavioural and physiological components (Gilbert, 2002). It has been considered largely as a trait, reflecting anxiety, anger and self-contempt, leading to negative automatic thoughts of the self as inferior, global and stable negative self-evaluation and social avoidance behaviours. Cognitive theorists have emphasized the link between negative self-schema and stigma consciousness (Gilbert, 1998), associated with the loss of positive affect, while in psychotherapy, shame has been understood as the avoidance of social injury. Evolutionary psychologists have regarded shame as an adaptive exhibition of submissive behaviour in the presence of more dominant others (Gilbert, 1997) and in appearance terms, the avoidance of contamination of the social group.

The role of shame in appearance dissatisfaction has attracted conceptual development. Kent (2000) and Kent & Thompson (2002) suggested a cognitive-behavioural model of the development and maintenance of disfigurement shame. This model details how self-schema involving shame might generate social anxiety, sensitize the person to rejection and make negative experiences easier to recall. Kent & Thompson (2002a, 2002b) and Thompson & Kent (2001) implied that individuals living with disfigurement are at considerable risk of experiencing feelings of internal and external shame. This model

has been applied to dermatological conditions as a means of conceptualizing domain-specific shame reactions, or “dermatological shame” (Kellett, 2002). If shame self-schema may mediate skin conditions and self-perceptions, dermatological shame may represent a core factor in the development of psychological difficulties. Kellett hypothesized 3 types of schematic change that transform global schema into shame-schema: schema reinforcement, schema attrition and schema vulnerability, arguing that dermatological shame can develop from early feelings of unattractiveness, negative social interaction or stigmatization (Gilbert 1992, 1998; Gilbert and Miles, 2002; Kellett and Gilbert, 2001). Kellett defined dermatological shame as “the inner emotional experience of the self as fundamentally unattractive to the self and others, vulnerable to rejection and put-down because of the state of the skin”, illustrating its affective nature. Dermatological shame may be maintained, like other cognitive schema, by processes such as attentional bias, avoidance, concealment (Koblenzer, 1997) and shame compensation. Kellett reported that people with acne use behavioural avoidance strategies to curb feelings of shame, although this can lead to social withdrawal. Koblenzer proposed that patients often feel “dirty” and may withdraw for fear of arousing disgust and rejection, whilst Kellett (2002) suggested that acne sufferers avoid attending appointments with sources of help due to fear of exposure and shame. Thompson *et al.* (2002) found that women living with vitiligo felt different and

suggested that social support served to facilitate the development of coping strategies associated with feeling of acceptance. Others may perceive shame schema subconsciously and a negative reciprocal response elicited, perpetuating the shame experience.

However, despite these findings and the current proliferation of psychodermatological literature, the conceptual status of dermatological shame remains tentative and little has been written regarding the role of shame in disfigurement (Thompson & Kent, 2001). This forms the basis of the study rationale.

### **3 STUDY RATIONALE**

Although dermatological shame appears to be a domain-specific phenomenon, no corresponding measure currently exists. Therefore, this paper aims to construct a Skin Shame Scale (SSS), and test its underlying factor structure. It was necessary to ascertain whether dermatological shame is a unifactorial or multifactorial concept and correspondingly, whether behavioural aspects, such as avoidance represent distinct factors. These questions were addressed through iterative factor analytic investigation.

There are a number of theoretical and clinical justifications for this study. Although there is growing recognition of the psychological impact of skin disease, there is less theoretical explanation as to how and why distress occurs. The effects of skin conditions are poorly understood, because the mechanisms leading to dermatological distress have not been investigated from a perspective based on psychological theory. The development of appearance distress measures has usually relied on empirical research, descriptive studies and expert opinion (Barankin & DeKoven, 2002), to the detriment of theoretical advancement. A number of existing generalised and body shame measures and measures of distress regarding appearance exist (Tangney, 1996), but none focus specifically on dermatological shame. Shame measures were of limited applicability as they contain no skin-specific items. The Derriford Appearance Scale (DAS-59: Carr *et al.*, 2000) assesses the distress experienced by people with appearance difficulties by general, social, sexual, body and facial factors, but does not pinpoint shame, focusing on self-consciousness, which may not possess the same affective intensity as shame. Bodily, rather than skin, shame is one of eight shame aspects explored in the Experience of Shame Scale (ESS: Andrews *et al.*, 2002). The SSS was constructed to compliment what Carr *et al.* described as the current paucity of outcome measures that has limited treatment evaluation

In order to address this, this study was theory-driven. Initial SSS items were based on the model of dermatological shame (Kellett, 2002), developed from the cognitive-behavioural model of disfigurement (Kent & Thompson, 2002). Avoidance and concealment behaviours were included as protective strategies against shame-triggering event, while items relating to stigma reflected their role in generating shame-schema. This was supported by the literature on external shame and the fear of others' judgment (Gilbert, 1998, Kent & Thompson 2002; Thompson & Kent, 2001). As psychological assessments and interventions have been indicated increasingly in dermatology, this scale was designed equally for its potential clinical utility.

#### **4 RESEARCH AIMS**

Therefore, the present study had the following research aims: (1) to construct the SSS, by the systematic selection of items that contribute significantly to dermatological shame; (2) to administer it to a large dermatological population; (3) to identify its underlying factor structures; (4) to begin to assess its internal reliability and (5) to begin to test its concurrent and divergent construct validity and criterion validity against other measures.



## **4.1 Hypotheses**

In order to determine the external validity of the SSS, six hypotheses were developed from the research aims.

1 The SSS will be moderately positively correlated with the Hospital Anxiety and Depression Scale (HADS: Zigmond & Snaith, 1983, see Appendix 3) and the Internalized Shame Scale (ISS: Cook, 1994, see Appendix 4). For the purposes of this study, the criterion of  $r = 0.60$  or above was used to describe a moderate correlation and applied to established scales and the SSS.

2 Women will score more highly on the SSS, HADS and ISS than men.

3 Patients with visible skin conditions (face or hands) will score more highly on the SSS, HADS and ISS than those with less visible conditions (body).

4 Self-reported severity (face, hands, body and total) will correlate more strongly with SSS, HADS and ISS than clinician-reported severity.

5 Patients will rate their skin conditions more severely than clinicians (face, hands, body and total severity).

6 Older patients will score less highly on the SSS, HADS and ISS than younger patients.

The research aims and hypotheses were addressed by the following procedures.

#### **4.2 Construction of the SSS**

The first stage in developing the SSS involved the selection of 30 items contributing to dermatological shame. The aim was to reduce this scale to a clinically useful index of 20-24 items.

#### **4.3 Item generation**

Generation methodology was used to develop items for the initial 30-item SSS (Wackerbarth *et al.*, 2002). This method involved collating potential items from multiple sources and employing systematic analysis to identify the most relevant. In psychodermatological research such a strategy has previously been used by Jowett &

Ryan (1985) to generate statements about individuals' self-consciousness regarding their skin.

Items related to skin shame were collated from: (a) interviews with dermatologists: (b) psychodermatological researchers and (c) existing measures, including the Experience of Shame Scale (ESS: Andrews *et al.*, 2002) and The Derriford Appearance Scale (DAS-59: Carr *et al.*, 2000).

The initial item list was analyzed by a multi-professional panel to enhance the comprehensiveness of items generated, and to minimise the omission of crucial items. Items within the initial 30-item SSS were developed under the factors suggested by the cognitive model of dermatological shame (Kellett, 2002), to enhance construct and content validity. These factors were envisaged as; "affect", "behaviour", "cognitions", "stigma" and "pride". Items were then ordered by these five factors to avoid generating a response set and an initial SSS containing 30-items formed. The SSS assessed participants' responses based on their feelings over the last week. Participants were asked to respond to items on a 5-point Likert-style response scale (Likert, 1932) ranging from "Never" to "Always". The initial 30-item initial SSS can be found in Appendix 5.

#### **4.4 Face and Content Validity**

In order to increase face and content validity and identify floor and ceiling effects, the initial SSS was piloted with 5 people with skin conditions. Respondents completed the questionnaire and were invited to comment on the items, instructions and response format. Problematic items were rejected and minor modifications made to the wording of remaining items and the revised 30-item SSS used in the study.

### **5 METHOD**

#### **5.1 Research Approval**

In order to proceed with the study, ethical Approval was obtained from the University of Sheffield's Research Sub-Committee (see Appendix 6) and from Barnsley Research Ethics Committee (see Appendix 7). Research indemnity was obtained from the Risk Management Department at Community Health Sheffield (see Appendix 8) and non-clinical trial insurance from the Department of Finance at the University of Sheffield (see Appendix 9). A target journal for publication was identified and the guidelines included in Appendix 10.

## **5.2 Participants and procedure**

Potential participants were those with chronic skin conditions attending initial and follow-up outpatients' appointments at Barnsley District General Hospital dermatology department, over a 6-month period (September 2003 to February 2004). A consultant dermatologist or nurse asked each participant whether they would like to take part in a study regarding how people felt about their skin. If they consented, they were offered the Research Information Sheet (Appendix 11). If, on reading this, they agreed to take part in the study, each participant completed the Research Consent Form (see Appendix 12).

One hundred and sixty-two participants completed a booklet of questionnaires, including the initial 30-item SSS, which were used in subsequent data analysis. Participants were given the option of completing this whilst at the clinic in the presence of the principal researcher, or returning it in a prepaid envelope.

## **5.3 Questionnaires**

The questionnaire booklet contained 4 measures: (1) the initial SSS; (2) a subjective index of the participant's skin disease measured on a scale of 1 to 10 (1 = "practically clear" to 10 = "in a bad state", called "A study into how you feel about your skin", see Appendix 13); (3) the Hospital Anxiety and Depression Questionnaire and (4) the Internalized Shame Scale. Simultaneously, each participant's nurse or consultant completed the same index of the participant's skin disease based on their clinical observations, called the Clinician Report Form (see Appendix 14).

The HADS is a well-validated measure for assessing anxiety and depression (Lewis & Wesley, 1990) and has been utilized in psychodermatological research as a predictor of mood (Fortune *et al.*, 2002a; Fortune, Richards, Kirby, Bowcock, Main, *et al.*, 2002b; Kellett & Gawkröger, 1999; Kirby *et al.*, 2000; Richards *et al.*, 2001), functional status and anxiety and depression in psoriasis (Fortune *et al.*, 2002a; Scharloo, Kaptein, Weinman, Hazes, Willems, 1998; Scharloo, Kaptein, Weinman, Bergman, Vermeer *et al.*, 2000). It has also been shown to be unbiased by physical symptomology, which was crucial in this setting. Cross-sectional research has demonstrated high reliability and validity and significant correlations between shame and depression measures such as the HADS. The ISS has been shown to have high reliability and construct validity (Cook, 1996; Cook & Campbell, 1979) and provided an additional measure of self-esteem, as it

includes the items comprising the Rosenberg self-esteem scale (RSES: Rosenberg, 1965). A score of 50 or over is indicative of possibly problematic levels of shame. The ISS has shown impressive reliability with clinical samples of people with anxiety (Cook, 1996; Turner & Lee, 1998).

Background data were also obtained pertaining to dermatological diagnosis and associated duration. Data from all 4 questionnaires in the booklet, along with those from the Clinician Report Form, were then entered into a database. SSS data were analyzed using principal axis and item analysis, as described below, and a final 24-item SSS constructed and used to test the research hypotheses.

## **6 RESULTS**

Firstly, this section reports the descriptive statistics of the study sample. The factorial validity of the SSS is then reported, the specific research hypotheses tested and inferential analysis undertaken.

### **6.1 Overview of Results**

Data analysis was conducted using the computer package SPSS version 11 to explore the relationships between variables, using the range of statistical tests described below. To reduce the probability of type 2 errors in this exploratory study, a significance level of  $p=0.05$  was used throughout the analysis. A table of the descriptive statistics of major variables can found in Appendix 15. All values are rounded up to 2 decimal places. Participant characteristics are described below.

## **6.2 Participant Characteristics**

The sample comprised of 101 women (62.3%) and 61 men (37.7%) with a mean age of 46 (SD = 18.95). The most prevalent self-reported skin conditions were psoriasis (55 participants, 34% of total sample), eczema (43, 26.5%) and acne (15, 2.3%) and their mean duration was 14.23 years (SD = 15.42). The mean prevalence of both depression and anxiety within this sample was approximately 13 %. Table 2 below indicates that, even when allowing for the greater ratio of women, this sample contained a greater proportion of females with acne than males, in contrast with existing studies (Kellett & Gawkröger, 1999).



### 6.3 Table 2: Dermatological diagnoses and gender

<b>Gender</b>	<b>Male</b>	<b>% of subset</b>	<b>Female</b>	<b>% of subset</b>
<b>Condition</b>				
<b>Psoriasis</b>	<b>25</b>	<b>45%</b>	<b>30</b>	<b>55%</b>
<b>Eczema</b>	<b>15</b>	<b>35%</b>	<b>28</b>	<b>65%</b>
<b>Acne</b>	<b>3</b>	<b>20%</b>	<b>12</b>	<b>80%</b>

### 6.4 Non-respondents

It was not possible to gather data on non-respondents, though the consultants reported anecdotally that they tended to be male and have lower educational status than participants.

### 6.5 Data analysis

Data analysis then proceeded in 4 stages: preliminary construct and criterion validity testing of the initial SSS using principal axis analysis, construction of the final 24-item

SSS, reliability testing of the final SSS, and investigation of related hypotheses using independent t-tests and correlational methods.

Initial inspection of the data suggested all variables were normally distributed, apart from the SSS total score, which was negatively skewed, implying that the distribution had a preponderance of high values. However, as the skew was not severe (Kolgorov-Smirnov = 0.20), it was decided not to transform the data, as this was likely to make interpretations of results problematic. The Kaiser-Meyer-Olkin measure suggested that sampling adequacy was satisfactory (0.890) and Bartlett's test of sphericity was significant (approximate chi-square 1781.20, significance 0.00).

Exploratory factor analysis (EFA), also termed principal axis analysis, was utilized to identify the latent variables possibly underpinning dermatological shame. This form of factor analysis is often used when attempting to understand underlying scale structure, which represented a central research aim (Brown, 1990; Tabachnick & Fidell, 1999, 2001). This sample satisfied the statistical rule of 150 participants for a principal axis analysis (Tabachnick & Fidell, 1999). Therefore, a frank exploration of the construct validity of the initial SSS was possible, in order to develop a final version of the scale.

## **6.6 Scale construction**

### **6.6.1 Validity of initial SSS**

In order to address the central research aim, the validity of the initial SSS was explored by means of principal axis analysis, item analysis and hypotheses testing for concurrent criterion validity.

### **6.6.2 Principal axis analysis**

A principal axis analysis was carried out on data from the 30 initial SSS items, employing the Kaiser-Guttman criterion, requiring eigenvalues to be greater than 1 for factor retention. In all cases, an iterative factor extraction method was used as factors were likely to be correlated above  $r = 0.40$  (Tabachnik & Fidell, 1999, 2001).

Inspection of the correlation matrix between the items suggested that the SSS was factorable, and therefore further analyses feasible, because a reasonable number of items exceeded 0.40 and Bartlett's sphericity test indicated that the null hypothesis that the variables were uncorrelated could be rejected.

Unrotated EFA found 8 factors exceeding 1.0, but the scree plot was ambiguous. The unrotated factor matrix of the 30 variables suggested that, while the majority of items loaded heavily onto factor 1, some cross-loaded moderately onto other factors. The EFA was therefore re-run once, using an orthogonal varimax rotation and once with an oblique rotation using the oblimin method. The varimax rotational technique has the advantage of simplifying factors by making high loadings higher and minimizing low loadings, thereby making the correlations between factor variables less ambiguous. Principal axis factoring with the varimax method obtained 8 factors with eigenvalues above 1, accounting for 66.46% of the total variance, of which a simple structure of 4 factors accounting for 51.20% seemed to describe the data adequately (Streiner, 1994). Although a 7 or 8-factor solution may have accounted for a greater proportion of variance, the 4-factor interpretation was more parsimonious. The eigenvalues above 1 for each factor, identifying identify factors that explain a significant proportion of variance, are represented in Table 2 and a more detailed representation of the factor loadings  $>0.4$  appears in Table 3, illustrating which items constituted the factors.

**6.6.3 Table 2: Eigenvalues above 1**

Factor	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	10.138	33.794	33.794	9.718	32.393	32.393	4.238	14.128	14.128
2	2.096	6.988	40.781	1.666	5.555	37.948	2.682	8.941	23.069
3	1.737	5.789	46.570	1.268	4.224	42.174	2.194	7.314	30.383
4	1.387	4.622	51.192	.914	3.045	45.219	1.801	6.004	36.387
5	1.247	4.189	55.381	.784	2.615	47.834	1.784	5.947	42.334
6	1.187	3.956	59.337	.712	2.373	50.206	1.687	5.622	47.956
7	1.108	3.694	63.031	.649	2.162	52.368	1.017	3.390	51.346
8	1.028	3.424	66.456	.628	2.092	54.460	.934	3.114	54.460

**6.6.4 Table 3: Factor Matrix (items contributing to factors emboldened)**

Summary of Item	Affective avoidance 1	Skin pride 2	Stigma 3	4	Behavioural avoidance 5	6	7	8
14 - worry	.743							
15 - thinking about	.630							
26 - despondent	.598							
13 - hiding	.589							
11 - ashamed	.588							
21 - worrying	.550		.427					
7 - different	.533		.403					
27 - avoid people touching	.504			.414				
3 - unattractive	.439		.418					
12 - avoid socialising	.439							
5 - rules life	.407		.405					
8 - beautiful		.776						
23 - as attractive		.638						
24 - I avoid touching		.624						
16 - proud	.412	.608						
28 - feel good								
6 - others stare			.644					
4 - avoid undressing			.517					
19 - avoid hoping								
20 - avoid contact				.644				
10 - like partner touching				.497				
2 - avoid mirror					.573			
25 - others avoid touching					.548			
17 - avoid discussing					.509			
9 - avoid treatment					.465			
1 - learnt to live						.640		
18 - people accept						.505		-.417
30 - one aspect						.489		
22 - contagious							.823	
29 - checking								.624

As in most exploratory analyses, factor 1 accounted for considerably more variance than subsequent factors (Floyd & Widaman, 1995). The first factor had an eigenvalue of 10.14 and accounted for 33.79% of the variance, comprising of 11 items pertaining to the negative affective components of skin distress, such as, “I am ashamed of my skin”, “I worry about how my skin appears”. Items were combined within a scale labelled *affective avoidance*.

The second factor accounted for 6.99% of the item variance (eigenvalue = 2.10) and comprised of 4 items concerning positive perceptions of skin disease such as, “My skin is as attractive as other peoples’”, and “I am proud of my skin”. These items produced a scale of *skin pride*.

The third factor (eigenvalue = 1.74, 5.80% of variance) contained 6 items relating to social avoidance, although 4 of these were cross-loaded onto factor 1, such as “others stare at my skin” and “I avoid undressing in front of people”, behaviour, which were combined to produce a scale of *stigma*.

Factor 5, containing 4 items and accounting for 4.19 of variance (eigenvalue = 1.26) was comprised of items relating to avoidance behaviour, such as “I avoid discussing/touching my skin” and produced a scale of *behavioural avoidance*.

Thus, the proposed factor structure was not obtained fully, although 4 of the suggested 5 factors of affect, skin pride, stigma and behavioural avoidance were identified. The anticipated cognitive factor of skin distress was not found in this study.

#### **6.6.5 Item analysis**

Item-total correlations using Cronbach’s Alpha were then applied to the identified subscales, so that those items accounting for the most variance could be retained and others excluded from the final SSS. Those sub-scales comprising of 5< factors were then tested for internal reliability; this criterion was employed as factors with less than 5 items are considered less reliable in EFA. Factors 1 and 3 were tested, therefore, and found to have good reliability of 0.92 and 0.84 respectively. Reliability analysis indicated that these factors had adequate internal reliability of 0.6 or over. It was then decided to examine factors 2 and 5, in case their internal consistency might be improved. Item-subscale analysis indicated that the consistency of factor 2 was high



(0.79) and that it could be improved in factor 5, from 0.68 to 0.70 by deleting factor 9, “I avoid getting treatment for my skin”. However, this was not considered a significant improvement and the item was retained. The increase in alpha deriving from deleting this item would have been less important than retaining it within length of the scale. Thus, the sub-scales were not amended by item analysis.

When factors were examined for cross-loadings, 4 of the items from factor 3, *stigma*, were found to cross-load onto factor 1, *affective avoidance*, albeit with weaker loadings. However, these factors were retained, as it was felt that a degree of cross-correlation between them might be expected. EFA and face validity were then used to exclude redundant items, as described below.

#### **6.6.6 Data reduction and final version of SSS**

However, EFA helped identify 2 items that loaded onto a factor containing only 1 item (items 22, “people think my condition is contagious” and 29, “I take every chance to check my skin) and 2 that did not factor (19, “I’ve given up hoping my skin will improve” and 28, “I avoid people touching my skin”). Item 10, “I like my partner to touch my skin intimately”, was removed as it was not applicable for all participants.

Therefore, these were removed from the final version of the SSS, along with item 21, “I worry about how my skin appears”, as this replicated item 14, “I worry how my skin looks to others”, but did not load as highly onto factor 1. Also, it cross-loaded onto factor 3. Thus, the final SSS was comprised of 24 items and can be found in Appendix 16. The 4 factors were intercorrelated in the factor correlation matrix in Table 4 below, which suggests a moderate degree of independence between the factors.

**6.7 Table 4: Factor Correlation Matrix**

		<b>Factor 1 – Affective avoidance</b>	<b>Factor 2 – Skin pride</b>	<b>Factor 3 - Stigma</b>	<b>Factor 4 – Behavioural avoidance</b>
<b>Factor 1 – Affective avoidance</b>	Pearson Correlation	1	.111	.073	.049
	Sig. (2-tailed)		.161	.355	.535
<b>Factor 2 – Skin pride</b>	Pearson Correlation	.111	1	.024	.065
	Sig. (2-tailed)	.161		.763	.414
<b>Factor 3 - Stigma</b>	Pearson Correlation	.073	.024	1	.029
	Sig. (2-tailed)	.355	.763		.719
<b>Factor 4 – Behavioural avoidance</b>	Pearson Correlation	.049	.065	.029	1
	Sig. (2-tailed)	.535	.414	.719	

**6.8 Reliability of the final SSS**

Two methods of internal consistency reliability estimates were employed; Cronbach’s coefficient alpha (Cronbach, 1951), which is a multipoint variation of the Kuder-

Richardson formula (Nunnally, 1970) and split-half reliabilities (Spearman-Brown formula). These methods showed that the full-scale initial SSS had good reliabilities of 0.92, and 0.88 respectively, placing them in the “high” correlation domain of  $r = 0.80$  or above (Anastasi, 1988). Item-full scale testing using an inclusion/deletion criterion of 0.5 showed that, as internal reliability was sufficiently high, no items needed to be removed on this criterion to increase it further.

### **6.8.1 Concurrent criterion validity of final SSS**

External-related criterion validity (Aitken, 1996) of the SSS was tested by using Pearson correlation coefficients ( $r$ ) between full-scale SSS scores and HADS and ISS scores as continuous variables, as the external criterion for the presence of psychological distress. The full scale SSS correlated significantly at the  $p = 0.01$  level with the HADS depression ( $r = 0.41$ ), HADS anxiety ( $R = 0.52$ ), HADS total score ( $r = 0.52$ ) and ISS shame ( $r = 0.57$ ), suggesting low to moderate external criterion validity, while the final full-scale SSS correlated negatively with the ISS self-esteem subscale at the 0.01 significance level ( $r = -0.47$ ,  $p = 0.000$ ). These results supported hypothesis 1, suggesting that the SSS was closely related to anxiety.

Correlational analysis showed that, of the 4 factor sub-scales, factor 1, representing affective avoidance, correlated moderately with the HADS total and anxiety scales and with the ISS shame scale, but was negatively correlated with the self-esteem subscale of the ISS ( $r = -0.29$ ,  $p = 0.000$ ). As this factor explained a greater proportion of variance than other factors, it was used in subsequent criterion analyses. As expected, item 14, with the highest loading on factor 1, correlated most strongly with the HADS total and anxiety scales and ISS shame scale. It was significantly, though moderately correlated with the HADS depression scale. A table of correlations between the initial SSS items, HADS sub and total scales and the ISS can be found in appendix 17, illustrating the satisfactory number of significant correlation between the final 24 items of the SSS, the HADS sub and total and ISS total scores.

## **6.9 Hypotheses testing**

Hypothesis testing was then carried out using the final 24-item SSS. The external validity testing demonstrated that the full-scale SSS was indeed moderately correlated with the HADS depression, anxiety and total scores and negatively correlated with the ISS self-esteem score at the 0.01 significance level ( $r = -0.47$ ). Factor 1, affective avoidance, correlated with the HADS total score at the 0.05 level ( $r = 0.18$ ) and even

more highly with HADS anxiety ( $r = 0.41$ ,  $p = 0.01$ ). Hypothesis 1 was therefore upheld. When equality of variances were assumed according to Levene's test, independent t-tests showed that women scored more highly than men on the full-scale SSS and affective avoidance subscale at  $p = 0.01$  and on the HADS total score and ISS shame scale, as shown in table 4 below. This result occurred despite there being no significant difference in self-reported total disease severity scores. Hypothesis 2 was, therefore, upheld.

**6.9.1 Table 5: Mean differences in scores by gender**

<b>Gender</b>	<b>Mean difference</b>	<b>T score</b>	<b>Significance</b>
<b>Scale</b>			
<b>Final full-scale</b>	<b>6.83</b>	<b>2.40</b>	<b>0.17</b>
<b>SSS</b>			
<b>Factor 1 affective avoidance</b>	<b>0.32</b>	<b>2.21</b>	<b>0.28</b>
<b>HADS depression</b>	<b>1.93</b>	<b>1.92</b>	<b>0.06</b>
<b>HADS anxiety</b>	<b>1.04</b>	<b>2.91</b>	<b>0.004**</b>
<b>HADS total</b>	<b>3.09</b>	<b>2.78</b>	<b>0.006**</b>
<b>ISS shame</b>	<b>9.97</b>	<b>3.12</b>	<b>0.002**</b>

\* $p < 0.05$

\*\* $p < 0.01$

Thus, table 5 highlights the significant differences between male and female participants in terms of their anxiety and shame scores. Using correlational methods, patients with visible skin conditions on the face and hands were not found to have significantly higher SSS scores than those with skin conditions on the body, by either self or clinician report. In fact, severity scores for face, body and total severity were found to be very similar according to clinician and self-report, hand severity scores being slightly lower. Therefore, hypothesis 4 was rejected. Correlational methods did indeed demonstrate that self-reported severity scores correlated significantly better with the full-scale SSS, affective avoidance subscale, HADS total and subscales and ISS shame scale than clinician-reported scores. Self-reported facial, body and total severity also correlated with the SSS at the 0.01 level ( $r = 0.32, 0.32$  and  $0.40$  respectively). However, full-scale SSS scores showed no significant relationship with clinician-rated severity. As anticipated, self-reported total severity correlated positively with ISS shame ( $r = 0.29$ ) and negatively with the self-esteem subscale of the ISS ( $r = -0.29$ ), both at the 0.01 significance level, whereas there was no significant correlation between clinician-

reported severity, the ISS or self-esteem. Hypothesis 5 that self-reported severity is better correlated with distress scores than clinician ratings was therefore upheld, as illustrated by the higher number of significant correlations in table 6 below.

**6.9.2 Table 6:**

**Correlations between self and clinician-reported disease severity ratings and distress**

<b>Correlation (r)</b>	<b>Self-report</b>	<b>Clinician-report</b>
<b>Scale</b>		
<b>Final full-scale</b>	<b>0.40*</b>	0.10
<b>SSS</b>		
<b>Factor 1 – affective avoidance</b>	0.13	-0.10
<b>HADS depression</b>	<b>0.25*</b>	-0.01
<b>HADS anxiety</b>	<b>0.30*</b>	-0.04
<b>HADS total</b>	<b>0.31*</b>	-0.05
<b>ISS</b>	<b>0.29*</b>	-0.10

\*p = 0.05 indicates significant difference between scores

Pearson's analysis indicated a correlation of  $r = 0.46$  between total severity as scored by the patient and clinician, which was significant at the 0.01 level, meaning that the null hypothesis could not be rejected. Spearman's correlations between participants' ages as a continuous variable and SSS scores showed that a negative correlation existed at  $r = -0.18$ , this correlation being significant at the  $p = 0.05$  level, upholding hypothesis 6. An overview of both the EFA and hypotheses testing will be offered below.

## **7 DISCUSSION**

The aim of this study was to construct a measure of dermatological shame and begin preliminary investigations into its validity and reliability. This section describes the study's implications and how the results relate to the research aims and hypotheses. Methodological, theoretical and clinical considerations and will also be discussed,

### **7.1 Implications of the present study**

This study is the first to attempt to develop a psychodermatological measure pertaining to shame. Models of shame relating to dermatology and disfigurement (Kellett, 2002;



Kent & Thompson, 2002) were utilized to construct a scale that was subjected to principal axis analysis to inform its theoretical construct. This demonstrated that the measure consisted of more than one subscale, rather than supporting an independence model that all variables showed independence, i.e. were unrelated (Tabachnik & Fidell, 1999). Validity and reliability analyses suggested that the SSS is a promising psychometric index of psychodermatological distress, which is related to the concept of dermatological shame. The factor structure extracted illustrated that the SSS had robust construct validity, and reflected the anticipated factors based on cognitive models of disfigurement, although it did not replicate the proposed five factors model, due to the cognitive aspect of dermatological shame failing to factor effectively.

In terms of external criterion validity, the final full scale SSS correlated well with the HADS and ISS. A moderate correlation between, the affective avoidance factor, HADS sub and full scales and the ISS was also found. Both the full-scale SSS and the affective avoidance subscale showed strong negative correlations with the ISS self-esteem subscale, suggesting discriminative validity. Content validity was enhanced by item generation, each item being endorsed by an adequate proportion of participants (5% or more).

The mean prevalence of clinically significant depression and anxiety within this sample (approximately 13 %) was comparable with that found in one existing studies (Picardi *et al.*, 2003) but lower than the average of around 24% across others. Using a cut-off of 11 on either HADS subscale (Love *et al.*, 2002), ten participants indicated depression (6.17% of sample), of whom 8 were female (80% of this subgroup), while 31 reported scores suggestive of clinical anxiety (19.14%), 24 being female (77.42% of subgroup). It is possible that existing studies included patients with some degree of pre-existing morbidity, or that their results related to different assessment tools, for example, Picardi *et al.* (2000, 2003) employed the GHQ-12 (Goldberg, 1972), which may have yielded differing prevalence. Like existing research (Schmid, 1996), this study illustrated the higher prevalence of affective disorders in women than men, especially of anxiety and internalized shame, despite their similar disease severity scores. The higher prevalence of anxiety in this sample suggested that it may represent a greater component of skin distress than depression, while the high correlation between ISS shame and HADS anxiety suggested that skin distress relating to shame-proneness correlated highly with anxiety responses in this sample. ISS shame was also highly correlated with HADS depression, indicating the salience of low mood in skin-related distress. Other participants may have been experiencing significant but sub-clinical levels of skin-related psychological distress, which is perhaps more reflective of the 24-33% of

dermatology patients with psychosocial difficulties suggested by Gupta & Gupta (2001a, 2001b) and Ginsberg (1996). It is possible that participants had pre-existing anxiety and depression that were not due to skin issues, which may have compounded their skin-related distress.

In terms of hypotheses, the salience of gender on skin-related distress levels was borne out, while the effects of disease location and age were less conclusive. The sample contained a greater proportion of women, which appears typical of dermatology outpatients' services (personal communication, 16<sup>th</sup> December, 2003). However, the results suggested that they experience more skin-related distress and anxiety than their male counterparts, independent of disease severity. Testing of the disease location hypotheses suggested that the face and body were more closely associated with skin distress than the hands, which was consistent with findings that facial symptomology appear to heighten psychological distress (Papadopoulos *et al.*, 2000). The relatively small size of the hands may suggest that disease coverage is more strongly linked with distress than location. The result indicating that age was negatively correlated with skin distress, perhaps supports the notion that aging, although not altogether negating skin-related distress, is predictive of adjustment. The significance of the relationship between self-reported disease severity and skin-related distress was strongly upheld and appears

to endorse the idea that subjective perceptions are crucial in determining the extent and nature of distress (Scharloo *et al.*, 1998).

It would be premature to assume that the mediating mechanisms of skin distress leading to psychological distress are exclusively shame-based as no causal inferences can be made in a cross-sectional study. However, these results do suggest that women with skin conditions may be more shame prone than men and that self-reported severity is a better predictor of skin distress than clinician ratings. The high prevalence of anxiety also reflects the literature around the clinical assessment of dermatology outpatients (Richards *et al.*, 2003).

## **7.2 Theoretical issues**

These results suggest that the distress felt by some people with skin conditions is closely related to cognitive models of shame, but suggested that many people with skin conditions, even those who are distressed, undergo a degree of adjustment to their skin condition and retain some sense of pride in their skin. This may be because not all areas of their skin are affected by the disease. It could be argued on the basis of this study, that both anxiety and shame mediate the psychological effects of skin conditions, which

is moderated by others' reactions in the form of stigma, and that pride and adjustment may protect against the development of skin distress.

Using items from different shame dimensions demonstrated that people living with skin conditions could experience shame in one or more, but not all, domains. This endorsement of the conceptual status of dermatological shame upholds Andrews *et al.*'s (2002) suggestion that it is valuable to divide shame into domains for research purposes and it is worthy of further exploration regarding the relationship between skin conditions and distress. A cognitive factor describing, perhaps, skin checking compulsions and fear of exposure was anticipated but not found, perhaps because the initial SSS contained insufficient items to tap into this phenomenon and the future expansion of cognitive items might prove useful. Despite this, the final SSS appears a meaningful measure of skin distress that provides some explanation of the individual's experiences, rather than being explicitly and therefore narrowly symptom-based.

### **7.3 Clinical implications**

The final SSS is potentially a clinically informative, brief and multidimensional screening tool that may help clinicians to target the specific distress of people with skin

conditions with individualised interventions. In conjunction with clinical assessment, the SSS may be able to differentiate individuals in terms of psychological interventions, thus addressing Carr *et al.*'s (2000) call for clinically and psychometrically robust scales.

#### **7.4 Methodological Limitations**

Measure, participant and sample characteristics represented methodological issues of concern in this study. Perhaps the most significant was that the SSS was not subjected to test-retest reliability analysis, as participants were actively undergoing treatment that was likely to have confounded these results, although its reliability was examined by other means. There is a risk in health settings that the HADS depression score may have been confounded by physiological fatigue symptoms, while the ISS lacked face validity with participants. The assessment of shame might be improved by the inclusion of an alternative measure, such as Andrews *et al.*'s Experience of Shame Scale (2002). It is also possible that nurses and dermatologists may have provided different interpretations of disease severity, which might be controlled for by using reports from one professional group. The issue of common method variance must also be considered when evaluating external validity analyses of the final SSS.

## 8 CONCLUSION

This study appears to have largely addressed its research aims of constructing the SSS, administering it to a large dermatological population, and beginning to examine its psychometric properties though further investigations into aspects of its reliability and validity are necessary. The development of the SSS has begun to consolidate the theory of dermatological shame and added to the understanding of the mechanisms of skin distress. The final version of the SSS is brief and seemed meaningful to participants and appears promising as a measure of psychological distress in dermatological conditions. Further research into the emotional and psychological factors surrounding chronic skin disease demands well-controlled empirical investigation. It is hoped that the development of this measure might widen the field of clinical enquiry into the psychological distress reported by dermatology patients and consolidate the breadth of measures available to evaluate interventions.

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## APPENDIX 3: HOSPITAL ANXIETY AND DEPRESSION SCALE



# Hospital Anxiety and Depression Scale (HADS)



Name: \_\_\_\_\_ Date: \_\_\_\_\_

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings he or she will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Read each item below and underline the reply which comes closest to how you have been feeling in the past week. Ignore the numbers printed at the edge of the questionnaire.

Don't take too long over your replies, your immediate reaction to each item will probably be more accurate than a long, thought-out response.

FOLD HERE

FOLD HERE

A	D	A	D
<p>I feel tense or 'wound up'</p> <p>Most of the time</p> <p>A lot of the time</p> <p>From time to time, occasionally</p> <p>Not at all</p>	<p>I feel as if I am slowed down</p> <p>Nearly all the time</p> <p>Very often</p> <p>Sometimes</p> <p>Not at all</p>	<p>3</p> <p>2</p> <p>1</p> <p>0</p>	<p>3</p> <p>2</p> <p>1</p> <p>0</p>
<p>I still enjoy the things I used to enjoy</p> <p>Definitely as much</p> <p>Not quite so much</p> <p>Only a little</p> <p>Hardly at all</p>	<p>I get a sort of frightened feeling like 'butterflies' in the stomach</p> <p>Not at all</p> <p>Occasionally</p> <p>Quite often</p> <p>Very often</p>	<p>0</p> <p>1</p> <p>2</p> <p>3</p>	<p>0</p> <p>1</p> <p>2</p> <p>3</p>
<p>I get a sort of frightened feeling as if something awful is about to happen</p> <p>Very definitely and quite badly</p> <p>Yes, but not too badly</p> <p>A little, but it doesn't worry me</p> <p>Not at all</p>	<p>I have lost interest in my appearance</p> <p>Definitely</p> <p>I don't take as much care as I should</p> <p>I may not take quite as much care</p> <p>I take just as much care as ever</p>	<p>3</p> <p>2</p> <p>1</p> <p>0</p>	<p>3</p> <p>2</p> <p>1</p> <p>0</p>
<p>I can laugh and see the funny side of things</p> <p>As much as I always could</p> <p>Not quite so much now</p> <p>Definitely not so much now</p> <p>Not at all</p>	<p>I feel restless as if I have to be on the move</p> <p>Very much indeed</p> <p>Quite a lot</p> <p>Not very much</p> <p>Not at all</p>	<p>0</p> <p>1</p> <p>2</p> <p>3</p>	<p>3</p> <p>2</p> <p>1</p> <p>0</p>
<p>Worrying thoughts go through my mind</p> <p>A great deal of the time</p> <p>A lot of the time</p> <p>Not too often</p> <p>Very little</p>	<p>I look forward with enjoyment to things</p> <p>As much as I ever did</p> <p>Rather less than I used to</p> <p>Definitely less than I used to</p> <p>Hardly at all</p>	<p>3</p> <p>2</p> <p>1</p> <p>0</p>	<p>0</p> <p>1</p> <p>2</p> <p>3</p>
<p>I feel cheerful</p> <p>Never</p> <p>Not often</p> <p>Sometimes</p> <p>Most of the time</p>	<p>I get sudden feelings of panic</p> <p>Very often indeed</p> <p>Quite often</p> <p>Not very often</p> <p>Not at all</p>	<p>3</p> <p>2</p> <p>1</p> <p>0</p>	<p>3</p> <p>2</p> <p>1</p> <p>0</p>
<p>I can sit at ease and feel relaxed</p> <p>Definitely</p> <p>Usually</p> <p>Not often</p> <p>Not at all</p>	<p>I can enjoy a good book or radio or television programme</p> <p>Often</p> <p>Sometimes</p> <p>Not often</p> <p>Very seldom</p>	<p>0</p> <p>1</p> <p>2</p> <p>3</p>	<p>0</p> <p>1</p> <p>2</p> <p>3</p>

Now check that you have answered all the questions

TOTAL

## APPENDIX 4: INTERNAL SHAME SCALE

# ISS

Name: \_\_\_\_\_

Date: \_\_\_\_\_

Below is a list of statements describing feelings or experiences that you may have from time to time or that are familiar to you because you have had these feelings and experiences for a long time. Most of these statements describe feelings and experiences that are generally painful or negative in some way. Some people will seldom or never have had many of these feelings.

Everyone has had some of these feelings at some time, but if you find that these statements describe the way you feel a good deal of the time, it can be painful just reading them. Try to be as honest as you can in responding.

Read each statement carefully and circle the number to the right of the item that indicates the frequency with which you find yourself feeling or experiencing what is described in the statement.

Use the scale below. DO NOT OMIT ANY ITEM.

	Never	Seldom	Sometimes	Often	Almost always
1. I feel like I am never quite good enough	0	1	2	3	4
2. I feel somehow left out	0	1	2	3	4
3. I think that people look down on me	0	1	2	3	4
4. All in all, I am inclined to feel that I am a success	0	1	2	3	4
5. I scold myself and put myself down	0	1	2	3	4
6. I feel insecure about others' opinions of me	0	1	2	3	4
7. Compared to other people, I feel like I somehow never measure up	0	1	2	3	4
8. I see myself as being very small and insignificant	0	1	2	3	4
9. I feel I have much to be proud of	0	1	2	3	4
10. I feel intensely inadequate and full of self doubt	0	1	2	3	4
11. I feel as if I am somehow defective as a person, like there is something basically wrong with me	0	1	2	3	4
12. When I compare myself to others I am just not as important	0	1	2	3	4
13. I have an overpowering dread that my faults will be revealed in front of others	0	1	2	3	4
14. I feel I have a number of good qualities	0	1	2	3	4
15. I see myself striving for perfection only to continually fall short	0	1	2	3	4



	Never	Seldom	Sometimes	Often	Almost always
16. I think others are able to see my defects	0	1	2	3	4
17. I could beat myself over the head with a club when I make a mistake	0	1	2	3	4
18. On the whole, I am satisfied with myself	0	1	2	3	4
19. I would like to shrink away when I make a mistake	0	1	2	3	4
20. I replay painful events over and over in my mind until I am overwhelmed	0	1	2	3	4
21. I feel I am a person of worth, at least on an equal plane with others	0	1	2	3	4
22. At times I feel like I will break into a thousand pieces	0	1	2	3	4
23. I feel as if I have lost control over my body functions and my feelings	0	1	2	3	4
24. Sometimes I feel no bigger than a pea	0	1	2	3	4
25. At times I feel so exposed that I wish the earth would open up and swallow me	0	1	2	3	4
26. I have this painful gap within me that I have not been able to fill	0	1	2	3	4
27. I feel empty and unfulfilled	0	1	2	3	4
28. I take a positive attitude toward myself	0	1	2	3	4
29. My loneliness is more like emptiness	0	1	2	3	4
30. I feel like there is something missing	0	1	2	3	4

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## APPENDIX 5: SSS INITIAL VERSION

### SSS (Initial version)

ID no. \_\_\_\_\_

Date-----

Here is a list of statements describing feelings and experiences about your skin that you may or may not have. Many people have had these feelings at some time while others will rarely or never have had these feelings. Please try to be as honest as you can in responding to each statement.

Please read each statement carefully and circle the number on the right that best describes how often it has applied to you over the last week.

	Never	rarely	sometimes	often	always
1. I've learnt to live with my skin condition	1	2	3	4	5
2. I avoid looking at my skin the mirror	1	2	3	4	5
3. My skin looks unattractive	1	2	3	4	5
4. I avoid undressing in front of people	1	2	3	4	5
5. My skin condition rules my life	1	2	3	4	5
6. Others stare at my skin	1	2	3	4	5
7. My skin makes me different	1	2	3	4	5
8. My skin is beautiful	1	2	3	4	5
9. I avoid getting treatment for my skin	1	2	3	4	5
10. I like my partner to touch my skin intimately	1	2	3	4	5
11. I am ashamed of my skin	1	2	3	4	5
12. I avoid socialising because of my skin	1	2	3	4	5
13. Hiding my skin makes me feel better	1	2	3	4	5
14. I worry how my skin looks to others	1	2	3	4	5
15. I find myself thinking about my skin	1	2	3	4	5
16. I am proud of my skin	1	2	3	4	5
17. I avoid discussing my skin	1	2	3	4	5
18. I believe that people accept my skin	1	2	3	4	5
19. I've given up hoping my skin will improve	1	2	3	4	5
20. I avoid intimate contact because of my skin	1	2	3	4	5
21. I worry about how my skin appears	1	2	3	4	5

22.	People think my condition is contagious	1	2	3	4	5
23.	My skin is as attractive as other peoples'	1	2	3	4	5
24.	I avoid touching my skin	1	2	3	4	5
25.	I can control my skin condition	1	2	3	4	5
26.	I feel despondent about my skin	1	2	3	4	5
27.	I avoid people touching my skin	1	2	3	4	5
28.	I feel good when people touch my skin	1	2	3	4	5
29.	I take every chance to check my skin	1	2	3	4	5
30.	My skin condition is only one aspect of me	1	2	3	4	5

APPENDIX 6: LETTER OF APPROVAL FROM SHEFFIELD UNIVERSITY  
RESEARCH ETHICS SUB-COMMITTEE





**THE UNIVERSITY OF SHEFFIELD**  
**Clinical Psychology Unit**  
**Department of Psychology**

Doctor of Clinical Psychology (DClin Psy) Programmes (Pre-registration and post-qualification)  
 Clinical supervision training and NHS research training and consultancy

Clinical Psychology Unit  
 Department of Psychology  
 University of Sheffield  
 Western Bank  
 Sheffield S10 2TP UK

Telephone: ++44 (0)114 22 26632  
 Fax: ++44 (0)114 22 26610  
 Email: dclinpsy@sheffield.ac.uk

Unit Director: Prof Graham Turpin (26569)  
 Clinical Practice Director: Ms Joyce Scaife (26574)

Assistant Director: Professor Pauline Slade (26568)  
 Course Administrator: Carole Gillespie (26570)

To: Research Office  
 Sheffield Health & Social Research Consortium  
 Fulwood House  
 Old Fulwood Road  
 Sheffield S10 3TH

**RESEARCH THESIS**

**Approval of Research Project**

Trainee name ..... CAROLINE SCOTT  
 University Research Supervisor ..... GERRY KENT  
 Title of Research Project  
CONSTRUCTING A SKIN SHAME SCALE  
 .....

I confirm that this research project has been reviewed by the Research Sub-Committee and all necessary amendments have been made. The project therefore receives full approval from the Course.

Signed .....  ..... Date ..... 9/6/03 .....  
 (University Research Supervisor)

Signed .....  ..... Date ..... 9/6/03 .....  
 (Course Research Tutor)



APPENDIX 7: LETTER OF APPROVAL FROM BARNSLEY RESEARCH ETHICS  
COMMITTEE



## APPENDIX 8: RESEARCH INDEMNITY



Risk Management Department  
Fulwood House  
Old Fulwood Road  
Sheffield  
S10 3TH

**Date:** 1<sup>st</sup> July 2003  
**To:** Caroline Scott  
**Department:** Clinical Psychology, Sheffield University  
**Ref:** SB/pj/Indem20

---

**Research Protocol Indemnity**

**Name of Investigator:** Caroline Scott  
**Department:** Clinical Psychology, Sheffield University  
**Title:** Constructing a Skin Shame Scale  
**Commencement Date:** 1<sup>st</sup> July 2003

On the basis that:

- The project receives Ethics Approval.
- Is subject to peer review and research governance.
- The relevant service is aware of its existence and supports the proposal.

then the project will form part of the ordinary working activity of the Trust and as such will fall within the terms of the liability cover provided by the NHSLA.

Shelagh Bostock  
Acting Director of Risk Management Department

Cc R Dixon

## APPENDIX 9 NON-CLINICAL TRIAL INSURANCE

UNIVERSITY OF SHEFFIELD

DEPARTMENT OF FINANCE

To Caroline Scott Date 09-Jul-03

Department Clinical Psychology

---

**Certificate of Insurances (non clinical trial)**

Trial Number NCT02/442

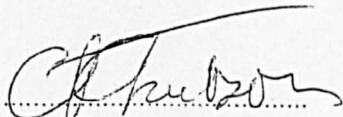
Department Clinical Psychology

Title of Trial Constructing a skin shame scale

Name of Investigators C Scott, Dr S Kellett, Dr R Sabroe  
Dr G Sobey, Dr D Gawkröger

Commencement Date Aug-03

The University has in place insurance against liabilities for which it may be legally liable and this cover includes any such liabilities arising out of the above research project/study

  
.....  
C.F. Jackson, Financial Accountant (Insurances)

**Please Note** 1. If not already provided please forward a copy of the Ethics Committee Approval as soon as possible

2. A record of the names of all participants, copies of signed Consent Forms and G.P.'s approvals should be retained by the Department.

NCT





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2. Smith, A.P., Tyrrell, D.A.J., Coyle, K.B., Higgins, P.G. and Willman, J.J. (1990) Individual differences in susceptibility to infection and illness following respiratory virus challenge. *Psychology and Health*, 4, 201-211.

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## PAGE CHARGES

**INFORMATION SHEET**

**A STUDY INTO HOW YOU FEEL ABOUT YOUR SKIN**

**Who is conducting this study?**

Caroline Scott, a Trainee Clinical Psychologist at Sheffield University, in collaboration with Drs David Gawkröger, Ruth Sabroe and Glenda Sobey, Consultant Dermatologists.

**What is this study for?**

This study will look at the relationship between skin condition and how they can make people feel. Your responses will be used to construct a questionnaire.

**What are the benefits of this study?**

The questionnaire will be useful in helping researchers try to understand how people feel about their skin and improve treatment.

**What will be involved if I agree to take part in the study?**

This study will ask you questions about how you feel about your skin condition. The questions are written as statements. You can hand it back to Caroline Scott in the clinic, or complete it in your own time and return it in the envelope provided.

**Do I have to take part?**

No. You are free to refuse to take part in this study. Your treatment will not be affected in any way.

**Can I withdraw from the study?**

Yes. You can do this at any time and you do not have to give a reason.

**What other information will be collected in the study?**

You will be invited to complete 3 other short questionnaires. In all, the 4 questionnaires should take about 15-20 minutes of your time.

**Will the information I give be confidential?**

Yes. All answers in the questionnaire are treated with the strictest confidence. Your anonymous ID number means no names are used in reports, so no one can be identified. All questionnaires will be stored securely. We are interested in people with skin conditions as a group, not as individuals.

**What should I do if I need to talk with someone?**

If completing the questionnaires makes you want to talk to somebody, please contact the skin clinic to arrange an appointment or arrange an appointment with your GP.

**What if I'm feeling upset?**

If taking part in the study suggests you are very depressed, or you tell us this, the researcher will encourage you to discuss this with your consultant. In extreme cases, if you tell us about suicidal feelings, the researcher will advise you strongly to tell your consultant. If you choose not to, the researcher will seek your permission to inform the consultant before doing this on your behalf. If you do not give your permission, the researcher may choose to inform the consultant for your own safety.

**What if I would like more information?**

Please contact            *C SCOTT 0114 222 6576*  
                                      *(Trainee Clinical Psychologist)*  
                                      *DR R SABROE 01226 320 417*  
                                      *(Consultant Dermatologist)*  
                                      *DR SC KELLETT 01226 777914*

*(Clinical Psychologist/Research Supervisor)*  
*Dr A THOMPSON 0114 222 6570*  
*(Senior Clinical Psychologist/Research Supervisor)*  
*DR GERRY KENT 0114 222 6570*  
*(Senior Clinical Psychologist/Research Supervisor)*

**Dr Sabroe is a Consultant Dermatologist at Barnsley District Hospital. Caroline Scott is supervised in this study by Dr Kellett, Dr Thompson and Dr Kent. Dr Kellett is a Senior Clinical Psychologist employed in the Barnsley Community and Priority Services Trust. Dr Andrew Thompson and Dr Gerry Kent are Senior Clinical Psychologists, Clinical Lecturers and Research Supervisors on the Sheffield University Clinical Psychology training course. They work together on studies like this to increase knowledge about the psychological effect of skin conditions and improve ways of helping people cope with them.**

### **What if I have a complaint?**

If you have any cause to complain about any aspect of the way you have been approached or treated during the course of this study, in the first instance, please contact the Research Supervisors listed above. If this is not satisfactory, the normal National Health Service complaints mechanisms are open to you and are not compromised in any way because you have taken part in a research study. You can use the hospital complaints procedure through Dr Chris Welsh, Medical Director, on 0114 271 2178. You can also contact:

**The Sheffield Teaching Hospitals Patient Advice and Liaison Service,**  
*Janet Wainwright (Patient Representative) 0114 271 2450/1900,*  
**Barnsley District Hospital Complaints Manager**  
*Julian Harris – 01226 777 984/730 000*

### **What happens next?**

If you decide you would like to take part in this study, please fill in the Research Consent Form. We will then give you a booklet of questionnaires. If you choose to complete it later, please return it in the prepaid envelope provided.

**Thank you for taking the time to read this form.**

**RESEARCH CONSENT FORM**

*TITLE OF PROJECT: A STUDY INTO HOW YOU FEEL ABOUT YOUR SKIN*

**The patients should complete the whole of this sheet themselves. Please read the following questions and cross out Yes or No as necessary.**

*Have you read the Research Information Sheet?*                      **Yes**                      **No**

*Have you had an opportunity to ask questions and discuss this study?*  
**Yes**                      **No**

*Have you received satisfactory answers to all your questions?*  
**Yes**                      **No**

*Have you received enough information about this study?* **Yes**                      **No**

*Who have you spoken to? Dr    Mr.    Ms.....*

*(Do you give your permission for us to access your notes? **Yes**                      **No**)*

*Do you understand that you are free to withdraw from this study?*

- at any time
- without having to give any reasons for withdrawing
- and without any affects on your future treatment
- in extreme cases of distress, the researcher may inform your consultant

**Yes**                      **No**

Do you agree to take part in this study?                      *Yes*                      *No*

Signed.....Date.....

Name (IN BLOCK LETTERS).....

Signature of Witness.....

Thank you for taking the time to complete this form.

APPENDIX 13: SELF-REPORT FORM

**ID No.      A STUDY INTO HOW YOU FEEL ABOUT YOUR SKIN**

*This form gives you the chance to tell us how you feel about your skin.*

If your skin condition has a name, please write it here.....

How long have you had your skin condition?

Your sex.....Your age.....

Date.....2003

**These 3 short questions ask you to rate the extent of your skin condition on different parts of your body on a scale of 1 – 10, by ticking a number.**

*My face is:*

1	2	3	4	5	6	7	8	9	10
Practically free of problems								In a Bad State	

My *hands* are:

1	2	3	4	5	6	7	8	9	10
Practically free of problems								In a Bad State	

My *body* is:

1	2	3	4	5	6	7	8	9	10
Practically free of problems								In a Bad State	

**Thank you for taking the time to fill in this form.**

APPENDIX 14: CLINICIAN REPORT FORM



**ID No.:      A STUDY INTO HOW YOU FEEL ABOUT YOUR  
SKIN**

**Clinician Report Form**

**This form gives you the chance to rate the patient's skin condition.**

Diagnosis.....

**These 3 short questions ask you to rate the extent of the patient's skin condition on different parts of their body on a scale of 1 – 10, by ticking a number.**

The patient's *face* is:

1	2	3	4	5	6	7	8	9	10
Practically free of problems								In a Bad State	

The patient's *hands* are:

1 2 3 4 5 6 7 8 9 10  
Practically free of problems In a Bad State

The patient's *body* is:

1 2 3 4 5 6 7 8 9 10  
Practically free of problems In a Bad State

**Thank you for taking the time to fill in this form.**

#### APPENDIX 15: DESCRIPTIVE STATISTICS

	N	range	minimum	maximum	mean	Std. Error	Std. dev.	variance
age	162	87.00	16.00	88.00	45.5494	1.48907	18.95272	359.208
clinician-report body	162	9.00	1.00	10.00	4.7716	.2131	2.71246	7.357
clinician-report face	162	9.00	1.00	10.00	3.1667	.2015	2.56409	6.575
clinician-report hands	162	9.00	1.00	10.00	2.6481	.1730	2.20240	4.851
clinician-report total	162	27.00	3.00	30.00	10.5988	.4008	5.10080	26.018
duration of condition in years	162	69.00	1.00	70.00	14.2315	1.2112	15.41629	237.662
HADS anxiety	162	20.00	.00	20.00	7.1358	.3285	4.18145	17.485
HADS depression	162	17.00	.00	17.00	4.3210	.2656	3.37998	11.424
HADS total	162	37.00	.00	37.00	11.5309	.5508	7.01035	49.145
ISS self-esteem	162	27.00	3.00	30.00	15.2469	.3977	5.06242	25.628
ISS shame	162	105.00	.00	105.00	29.0679	1.5885	20.21810	408.772
self-report body	162	9.00	1.00	10.00	5.2963	.2139	2.72301	7.415
self-report face	162	10.00	.00	10.00	3.3086	.1943	2.47292	6.115
self-report hands	162	9.00	1.00	10.00	3.2963	.2175	2.76825	7.663
self-report total	162	27.00	3.00	30.00	12.0370	.3982	5.06834	25.688
Initial SSS total	162	126.00	12.00	138.00	84.0000	1.7734	22.57163	509.478
1- learnt to live	162	4.00	1.00	5.00	2.2593	.0945	1.20329	1.448
11- ashamed	162	4.00	1.00	5.00	2.6420	.1049	1.33569	1.784
12-avoid socialising	162	4.00	1.00	5.00	2.1728	.0945	1.20341	1.448
13- hiding	162	4.00	1.00	5.00	2.9568	.1070	1.36208	1.855
sss14-worry	162	4.00	1.00	5.00	3.1173	.1056	1.34389	1.806
sss15-thinking	162	4.00	1.00	5.00	3.2346	.0925	1.17713	1.386
sss16-proud	162	4.00	1.00	5.00	3.6543	.0948	1.20723	1.457
sss17- avoid discussing	162	4.00	1.00	5.00	2.2963	.0926	1.17895	1.390
sss18-people accept	162	4.00	1.00	5.00	2.6728	.0951	1.20985	1.464
Sss19-people accept	162	4.00	1.00	5.00	2.4877	.1011	1.28652	1.655
sss20-avoid intimate contact	162	11.00	1.00	12.00	2.4506	.1132	1.44055	2.075
sss23-as attractive	162	4.00	1.00	5.00	3.6543	.0936	1.19169	1.420
sss24- avoid touching	162	4.00	1.00	5.00	2.0741	.0925	1.17719	1.386

<b>sss25-control</b>	162	4.00	1.00	5.00	3.0617	.0942	1.19882	1.437
<b>sss26-despondent</b>	162	4.00	1.00	5.00	2.9506	.1046	1.33189	1.774
<b>sss27-avoid people touching</b>	162	4.00	1.00	5.00	2.6852	.1071	1.36264	1.857
<b>sss3-unattractive</b>	162	4.00	1.00	5.00	3.4568	.1014	1.29067	1.666
<b>sss30-one aspect</b>	162	4.00	1.00	5.00	2.3457	.1034	1.31556	1.731
<b>sss4- avoid mirror</b>	162	11.00	1.00	12.00	3.0123	.1162	1.47857	2.186
<b>sss5-rules life</b>	162	4.00	1.00	5.00	2.6728	.1028	1.30850	1.712
<b>sss6-others stare</b>	162	4.00	1.00	5.00	2.7531	.0975	1.24143	1.541
<b>sss7-different</b>	162	4.00	1.00	5.00	2.7469	.0996	1.26742	1.606
<b>sss8-beautiful</b>	162	4.00	1.00	5.00	3.8333	.0885	1.12703	1.270
<b>sss9-avoid treatment</b>	162	4.00	1.00	5.00	1.7531	.0817	1.03996	1.082
<b>Final SSS total</b>	162	87.00	27.00	114.00	66.9444	1.3968	17.77892	316.090

APPENDIX 16: SSS FINAL VERSION

SSS (final version)

ID No \_\_\_\_\_

Date: \_\_\_\_\_

Here is a list of statements describing feelings and experiences about your skin that you may or may not have. Many people have had these feelings at some time while others will rarely or never have had these feelings. Please try to be as honest as you can in responding to each statement.

Please read each statement carefully and circle the number on the right that best describes how often it has applied to you over the last week.

---

	Never	rarely	sometimes	often	always
1. I've learnt to live with my skin condition	1	2	3	4	5
2. I avoid looking at my skin the mirror	1	2	3	4	5
3. My skin looks unattractive	1	2	3	4	5
4. I avoid undressing in front of people	1	2	3	4	5
5. My skin condition rules my life	1	2	3	4	5
6. Others stare at my skin	1	2	3	4	5
7. My skin makes me different	1	2	3	4	5
8. My skin is beautiful	1	2	3	4	5
9. I avoid getting treatment for my skin	1	2	3	4	5
10. I am ashamed of my skin	1	2	3	4	5
11. I avoid socialising because of my skin	1	2	3	4	5
12. Hiding my skin makes me feel better	1	2	3	4	5
13. I worry how my skin looks to others	1	2	3	4	5
14. I find myself thinking about my skin	1	2	3	4	5
15. I am proud of my skin	1	2	3	4	5
16. I avoid discussing my skin	1	2	3	4	5
17. I believe that people accept my skin	1	2	3	4	5
18. I avoid intimate contact because of my	1	2	3	4	5
19. My skin is as attractive as other people	1	2	3	4	5
20. I avoid touching my skin	1	2	3	4	5
21. I can control my skin condition	1	2	3	4	5
22. I feel despondent about my skin	1	2	3	4	5

- |  |   |   |   |   |   |
|--|---|---|---|---|---|
| 23. I feel good when people touch my skin      | 1 | 2 | 3 | 4 | 5 |
| 24. My skin condition is only one aspect of me | 1 | 2 | 3 | 4 | 5 |

APPENDIX 17: CORRELATIONS BETWEEN FINAL SSS ITEMS, HADS SUB  
AND TOTAL SCALES AND SSS

<b>Correlation (r)</b> <b>item</b>	<b>HADS</b> <b>depression</b>	<b>HADS anxiety</b>	<b>HADS total</b>	<b>ISS</b>
<b>1-Learnt to live</b>	<b>0.31**</b>	<b>0.35**</b>	<b>0.37**</b>	<b>0.39**</b>
<b>2-Avoid mirror</b>	<b>0.26**</b>	0.16	<b>0.21**</b>	<b>0.24**</b>
<b>3-Unattractive</b>	<b>0.18*</b>	<b>0.33**</b>	<b>0.29**</b>	<b>0.30**</b>
<b>4-Avoid</b> <b>undressing</b>	0.05	0.10	0.10	<b>0.16*</b>
<b>5-Rules life</b>	<b>0.40**</b>	<b>0.48**</b>	<b>0.47**</b>	<b>0.43**</b>
<b>6-Others stare</b>	0.13	<b>0.22**</b>	<b>0.20*</b>	<b>0.22**</b>
<b>7-Different</b>	<b>0.20*</b>	<b>0.26**</b>	<b>0.24**</b>	<b>0.34**</b>
<b>8-Beautiful</b>	<b>0.36**</b>	<b>0.45**</b>	<b>0.45**</b>	<b>0.40**</b>
<b>9-Avoid</b> <b>treatment</b>	0.04	0.00	0.01	0.10
<b>11-Ashamed</b>	<b>0.30**</b>	<b>0.36**</b>	<b>0.36**</b>	<b>0.44**</b>
<b>12-Avoid</b> <b>socialising</b>	<b>0.34**</b>	<b>0.35**</b>	<b>0.80**</b>	<b>0.46**</b>

<b>13-hiding</b>	<b>0.17*</b>	<b>0.36**</b>	<b>0.29**</b>	<b>0.31**</b>
<b>15-Thinking</b>	<b>0.36**</b>	<b>0.52**</b>	<b>0.50**</b>	<b>0.49**</b>
<b>16-Proud</b>	<b>0.29**</b>	<b>0.40**</b>	<b>0.38**</b>	<b>0.40**</b>
<b>17-Avoid discussing</b>	<b>0.18*</b>	<b>0.19*</b>	<b>0.22**</b>	<b>0.30**</b>
<b>18-people accept</b>	<b>0.16*</b>	<b>0.22**</b>	<b>0.21**</b>	<b>0.26**</b>
<b>21-worrying</b>	<b>0.36**</b>	<b>0.31**</b>	<b>0.35**</b>	<b>0.40**</b>
<b>23-as attractive</b>	<b>0.27**</b>	<b>0.34**</b>	<b>0.38**</b>	<b>0.25**</b>
<b>24-I avoid touching</b>	<b>0.21**</b>	<b>0.19*</b>	<b>0.22**</b>	<b>0.21**</b>
<b>25-Others avoid touching</b>	<b>0.37**</b>	<b>0.38**</b>	<b>0.40**</b>	<b>0.30**</b>
<b>26-Despondent</b>	<b>0.33**</b>	<b>0.48**</b>	<b>0.468**</b>	<b>0.46**</b>



<b>27-I avoid</b>	<b>0.31**</b>	<b>0.32**</b>	<b>0.35**</b>	<b>0.38**</b>
<b>people touching</b>				
<b>30-One aspect</b>	0.13	0.12	0.13	<b>0.22**</b>

\*P<0.05

\*\*P<0.01

**CRITICAL APPRAISAL**

WORD COUNT 4421

## **CRITICAL APPRAISAL**

### **1 INTRODUCTION**

This section provides a critical appraisal of the present study, tracing it from its initial stages to its current stage of completion. The appraisal has four sections: (1) conception, (2) implementation (3) learning and development, including methodological limitations of the study, clinical implications, recommendations for further study and ethical issues (4) reflections on the research process, including on the current profile of psychology and the importance of supervisory relationships.

### **2 CONCEPTION**

During my time as a trainee clinical psychologist, there was an increased acknowledgement of the psychological impact of skin conditions within the NHS (All Party Parliamentary Group on Skin, 2003) and other agencies. This emphasized the need for research into the assessment of dermatological distress, in order that it is better understood, and effective interventions developed. It led, among other developments, to the formation of a psychodermatology group, comprising of psychologists, psychiatrists and dermatologists. This represented the first professional synthesis of psychology and

dermatology professionals and had its inaugural conference in May 2003 in London. In December 2003, the first conference of the Centre for Appearance Research was held in Bristol, to reflect the importance of appearance-related issues to theory, research and practice. The latter featured a keynote speech by a member of *Changing Faces*, who specialize in and support people around the psychosocial aspects of disfigurements, including those resulting from skin conditions. My academic supervisors were involved in both these events and had invited me along.

Though the psychodermatological movement was generating a number of papers on interventions, it transpired that there was only limited understanding of the mediating factors between dermatological conditions and psychological distress. It was concerning that those factors predictive of skin distress were poorly understood and had received little examination in relation to clinical psychology. Moreover, it was difficult to see how interventions could be efficacious without a clearer understanding of the psychological mechanisms of skin distress. A measure was needed to assess why some people with skin conditions became distressed, while others seemed to adjust and cope well.

During introductory research sessions in the first year of the Sheffield course, I was increasingly aware of my previous experience of eczema and of its considerable personal impact of my self-perceptions and social life. This was salient because of the stress engendered by course demands and its ongoing effects on my skin and that of my peers. Although this personal experience was distinct from my awareness of skin research, I was aware that there was considerable expertise around both health psychology and disfigurement within the department and that a previous trainee, Dr Kellett, working locally as a senior clinical psychologist, had proposed a theory of dermatological shame. Shame had also been identified as a key emotion by both my academic supervisors. I became keen to conduct a third year research project that would seek to bridge both areas. More importantly, this approach offered a theory-informed strategy that could contribute to psychodermatological interventions. One of the key challenges of the whole research process was to concentrate on creating a tool that could bring clinical benefit to individuals in distress and to allow myself to be motivated by this. The next stage involved consulting with my clinical supervisor to decide upon a structure and way forward.

### **3 IMPLEMENTATION**

After discussions with Dr Kellett, we agreed on the necessity to examine further the theory of dermatological shame in order to better assess the psychological impact of skin distress. At the same time, meetings with local consultant dermatologists in Barnsley arranged by Dr Thompson confirmed their belief in the salience of psychological factors to skin diseases and their interest in the study. Their stance on the role of psychological factors in skin distress facilitated a strong yet flexible working relationship that I feel endorsed the role of clinical psychology in dermatology clinics. The initial research proposal was completed and provisional consent to conduct the study at Barnsley District General Hospital Dermatology department obtained.

This study would use the theory of dermatological shame (Kellett, 2002) to construct a psychological instrument to assess skin distress. Dr Kellett and Dr Kent was keen to further explore this idea, in order to consolidate its conceptual status.

### **3.1 Literature Review**

Keen to present a strong rationale for the present study, I explored a number of areas of related literature, including shame assessment, psychological factors in cosmetic surgery and cosmetic rehabilitation. However, there was little interface between the shame assessment literature and health psychology, insufficient psychology-driven

studies into surgery and cosmetic rehabilitation was overly medical. Therefore, it seemed logical to focus the present review on evaluating existing scales that had attempted to assess the impact of skin conditions on individuals' lives.

Although I had some personal experience of living with a skin condition and an awareness of their psychological impact, I had to familiarize myself with the different perspectives from which skin distress had been assessed, for example, the theories of body image and stigma. It was often difficult to judge how far into each theory it was necessary to probe in order to make an informed evaluation of each scale. I usually acquired this knowledge by consulting book chapters recommended by my supervisors.

Moreover, it seemed to take a huge amount of effort and practice to understand the psychometric criteria by which I was to evaluate each scale, for example the subtle differences between construct and criterion validities. This often left me feeling deskilled and overly dependent on explanations from Dr Simpson, who provides statistical expertise to the department, which I imagined were both repetitive and monotonous for him. It did not help that textbooks on this subject often appeared to offer slightly different definitions. Reading through the original papers provided context in which to make sense of these concepts and I finally began to take an overview of

critical themes within the literature, learning as I went. Slowly, I began to accept that I did not need to comprehend everything fully in order to begin the research process, which allowed me to proceed with ethics procedures.

### **3.2 Ethical and Clinical Approval**

My experience of obtaining ethical approval from the University of Sheffield Research Sub-Committee and Barnsley Research Ethics Committee was somewhat more parsimonious and constructive than I had anticipated. This was doubtless the result of thorough examination of the research proposal by my supervisors and numerous subsequent amendments on my part.

The Research Sub-Committee suggested only that I abbreviated the questionnaire titles to minimize participants' potential negative affect about completing a shame scale. They endorsed the inclusion balance of shame-related and more positive items in the SSS. The Ethics Committee's concerns were also concerned largely on participants' well-being and safety, requiring a clearer protocol regarding clinically significant depression scores and suggesting that I check the scales further for readability. These concerns were addressed and seem likely to have facilitated implementation by improving the scales' face validity and increasing my confidence in dealing with any



risk issues. The granting of ethical approval, though crucial, did not feel like an achievement, as there was so much work yet to be completed.

### **3.3 Implementing the Project**

My recollection of the project proper was dominated by positive experiences of the participants. Remaining with them while they completed the questionnaires allowed me first-hand experience of their stories and conferred a number of advantages: I was able to address their queries, monitor the face validity of items, collect qualitative comments on the scales and feed back to the consultants if any participants appeared particularly distressed. Though shame scales have been criticized for an over-reliance on negative items, participants did not appear to find items based on “skin pride” meaningful. Conversely, my presence may have lengthened the process of data collection and influenced participants’ responses.

On balance, however, I believe that face-to-face contact with dermatology staff and outpatients enriched this thesis because I of my learning about skin conditions and their associated distress from their experience and my own. Hearing about patients’ experiences also underlined the need for a screening measure of skin distress. It was gratifying to learn that informing the consultants about those patients who met caseness

on the HADS was clinically useful. One of the consultants commented that although she was aware of many of them, the HADS had identified others whom she had not realized were significantly distressed and had been able to direct towards appropriate sources of support. Again, this was a timely reminder of the clinical meaningfulness of this research, which helped to motivate me when the process became turgid. A number of methodological issues relating to the more rigid process of scale development will now be explored below.

#### **4 LEARNING AND DEVELOPMENT**

It seems appropriate to begin this section with my considerable exposure to the SPSS computer package in the course of this study. I found my lack of basic statistical skill frustrating at times, but was encouraged by the creativity of the analytic process. I have begun to learn that meaningful statistical analysis requires synthesis between a science and an art, and there is often more than one appropriate way to investigate data.

In terms of professional development, I would say that my preoccupation seemed to detract from clinical considerations at times. I didn't feel like reading outside this thesis and would occasionally be distracted, say in supervision, by a pressing research query.

Luckily, I benefited from the support of a supervisor who knew only too well the potential strain of these sometimes conflicting demands. Together, we developed a structured yet flexible approach to time management that allowed me to prioritize, plan and crucially, pace tasks on a week-to-week basis. This understanding was vital to my well-being as it reassured me that no area of my work was being undersold.

It does not feel like sufficient time has yet elapsed since the hand-in date to evaluate fully the role of this thesis in my learning and development. It was often difficult to consider how it was contributing to my skills as a clinical psychologist and I suspect that this will only become clearer after some years spent as a qualified clinician. It came almost as a surprise when the dermatology consultants thanked me for my involvement in their department and requested that I presented my research to them and to a wider dermatology forum. On reflection, the pressure of the thesis time schedule means that it is easy to forget its clinical implications and potential application. This reminder served, therefore, as encouragement to ensure that the study was clinically useful to those who might read it.

My personal learning and development from this thesis remain similarly hazy, perhaps as my sense of achievement is incomplete. Writing this appraisal reminds me of the

pleasures of writing creatively and from personal experience, which may, one day, encourage me back into writing about my work as a psychologist. I suspect, however, that that might be from a more experiential perspective than this study. Perhaps this process of reflection will be facilitated further by another five years of clinical work, in which the indulgence of research may start to become an attractive distraction. Certainly, undertaking this project has developed my determination to secure CPD time and support as a qualified clinical psychologist, and inspired me to seek a position in a department which is research aware and active. This was by no means, my only reflection on the research process.

#### **4.1 Methodological limitations**

From a methodological perspective, this study had a number of limitations that further research might improve upon. The key areas for improving the study involve the use of measures, participant characteristics and generalisability. Ethical issues are also alluded to in this section.

##### **4.1.1 Measurement issues**

Using a clinical cut-off of 11 for HADS sub-scale scores was considered during data analysis to investigate the discriminative validity of the SSS between those participants meeting clinical “caseness” and those who did not. A score of eleven or above was used in its development as suggesting an increased probability of mood disorder, and is the recommended cut-off score (Love, Kissane, Bloch & Clarke, 2002) and has been shown to be a rigorous identification threshold (Love *et al.*, 2002; Martin & Thompson, 2000; Picardi, Abeni, Renzi, Braga, Melchi *et al.*, 2003), which increases the HADS’ predictive value. However, using a cut-off point on a continuous variable such as this would have resulted in a loss of statistical power and increased the probability of type 1 errors, by creating a false dichotomy between participants experiencing distress and those who were not. Therefore, HADS scores were treated as continuous variables for purposes of statistical testing. It is arguable that this method failed to provide a thorough examination of the SSS’s external validity and that this could have been investigated using a median-split division in HADS scores. It is possible that the omission of a cut-off failed to identify those participants with “borderline” anxiety and depression that might also have correlated with skin shame. However, though Richards, Fortune, Griffiths & Main (2001) argued that the HADS had low specificity in identifying clinically significant psychological morbidity, its generalisability in chronic illness,

brevity and wide utilization in clinical health settings seemed to make it the most appropriate instrument for this study.

Conversely, the ISS appeared to lack face validity within the sample population, perhaps due to its dearth of skin specific items. Many participants found its tone rather “catastrophic”, indicating, perhaps, that its usage is inappropriate outside mental health settings. Though it had been used in empirical research into shame, its lack of salience within dermatological populations may have meant that it failed to identify the constellation of emotions experienced by this group. Using a scale more meaningful to participants may have produced different effects, but the ISS was useful in determining the external validity of the SSS.

The SSS might be criticized on the grounds that it has few treatment-related items, such as compliance, that have been shown to contribute to psychodermatological distress (Fortune, Main, O’Sullivan & Griffiths, 1997). The perceptual disease severity indices used in this study may have been improved by employing a 100mm visual analogue scale to improve accuracy (Rapp, Cottrell & Leary, 2001). As all data was self-reported, the extraneous effects of common method variance contaminate the results of this study potentially, although clinical information was triangulated to some extent by the

inclusion of the clinician report measure. However, this methodology may have been advanced by the inclusion, perhaps, of disease and distress ratings from a significant other with knowledge of the participant's experience of living with a skin condition. Behavioural ratings might also have helped clarify the relationship between affective and behavioural avoidance.

#### **4.1.2 Participant Characteristics**

A number of factors regarding the study sample appear to affect the potential generalisability of results. As data was not collated regarding the number of patients asked to participate in this study and the proportion who refused, it cannot be assumed that this study is entirely representative of all dermatological outpatients. It may be that those patients experiencing the most skin distress were most likely to attend a dermatology outpatients' clinic and thus artificially increased the prevalence of skin distress in this sample. Conversely, non-response may have been indicative of high levels of distress. As it was not possible to collect detailed data for non-respondents, and there was no control group, it is unclear whether or not participants' levels of distress were representative of the dermatological population and how they compare with other populations. It would have been useful to compare data from this sample with patients from another chronic disease group, as Fortune, Richards, Kirby, Bowcock

& Main *et al.* (2002a) used a sample of patients with chronic fatigue, although the skin-specificity of the items may have rendered the SSS meaningless in non-dermatological contexts.

As participants were recruited over a relatively short period and were not self-selected, the potential for selection bias was minimized and narrow confidence intervals utilized. The wide diversity of participants' chronic dermatological conditions enhances the SSS's external validity, although it should be noted that the sample included few patients with vitiligo, a condition which has undergone research into skin disfigurements (Papadopoulos, Bor, Legg & Hawk, 1998; Papadopoulos, Bor & Legg, 1999a; Thompson, Kent & Smith, 2002), and shown markedly different results. Recruiting participants from other dermatology departments may have enhanced the ecological validity of this study and the generalisability of the results. The sample was culturally homogeneous and it would have been interesting to explore skin distress for people from cultures in which skin is more covered, for example. Investigating whether skin-related stigma and avoidance behaviours are reflected in societies in which skin is more concealed might inform the mechanisms of skin distress.



### **4.1.3 Ethical Considerations**

A number of ethical considerations regarding this study merit consideration. Self-assessment of skin conditions may have proved to be a distressing procedure to some participants. However, most items appeared to be meaningful to participants, replicating the findings of Carr, Harris & James (2000), who reported that none of their participants from a clinical population was distressed at the content of problem-oriented items. Participants may have reassured by the introductory section of the SSS that stressed that some items would be relevant to some respondents, but not others, re-iterating that shame is not inevitable consequence of skin conditions. Participants were safeguarded by informing them of the NHS complaints procedures and providing them with the opportunity to access further psychological support via their consultant. Offering them the option of completing the questionnaires at home gave patients an opportunity to opt out of the study at a second stage. Clear language helped make this research accessible for those participants who did not have English as their first language or read well and a number were able to complete the questionnaires with help. However, though not ideal in terms of diversity, it was not be possible to include participants for whom English

was not their first language because of the complexities of translating standardized questionnaires.

## **4.2 Clinical implications**

As reliability and validity testing of the SSS remains in its early stages, clinicians might view it with some caution, though its clinical meaningfulness to dermatological patients might be posited on the basis of this study. The brevity of the final 24-item SSS is comparable with existing psychodermatological measures, such as Skindex-29 (Chren, Lasek & Quinn, 1996) and may make it useful as a screening tool in primary and secondary, helping those who are most likely to benefit from psychodermatological treatment receive appropriate support. The SSS may allow clinicians to gather a relative breadth of information concerning psychodermatological distress within the least amount of clinical time, thus addressing the so-called “bandwidth-fidelity dilemma” (Cronbach & Gleser, 1965). Cronbach (1970) proposed, “When several questions are of about equal importance, it is more profitable to use a brief test giving a rough answer to each one, than to use a precise test answering only one or two questions” (p. 151). The SSS offers a multidimensional assessment of dermatological shame, including affective and behavioural domains and aspects of stigma and pride, which is central in understanding the experiences of those people with dermatological distress. Multi-

dimensionality also increases the content validity in the SSS by ensuring more aspects of living with a skin condition are included. Used in conjunction with clinical interviews, it may help provide an index of the degree and nature of presenting skin-related distress. It was decided not to determine a cut-off for clinical caseness on the SSS, but rather, to rely on clinical judgment and the information offered by individual items.

Though a body of literature exists around psychosomatic factors in chronic skin disease, especially in terms of aetiology (Panconesi, 2000), less has been written about the somatopsychic effects of skin conditions on the self and the emotional and social consequences of this. In short, there has been a bias in the directionality of psychodermatological writing to which this study may contribute. A body of research has suggested that people who are chronically anxious or depressed are more vulnerable to psychosomatic disease (Panconesi, 2000); whereas this study suggests that those with chronic disease may be more vulnerable to psychological disturbance. Subsequently, the findings of this study may help inform current cognitive-behavioural interventions, because they clarify to an extent which factors are most salient to individuals with skin disease, i.e. behavioural avoidance. As a protective factor of skin pride exists for some people, clinicians might work towards enhancing this. Research into cognitive-

behavioural management programmes as adjuncts in psoriasis therapy (Fortune et al., 2002a; Richards, Fortune, Main & Griffiths, 2003) has demonstrated reductions in psoriasis severity, depression and psoriasis-related stress. Group-work around issues such as anticipatory anxiety and social avoidance have also reduced symptoms and improved patients' moods, through exposure to the group in vivo, thus reducing the fear of stigmatisation. This study underlines the need to tackle stigma and behavioural avoidance in order to enhance clients' ability to cope, and deal with social situations. It also reinforces the need to tackle chronic anxiety in many of this client group, in order to manage their condition and perhaps reduce symptoms in the process.

### **4.3 Further research**

In the context of the study findings, the further conceptual development of skin-related distress is necessary to pinpoint the unique experience of some individuals with chronic skin conditions. Further studies of the SSS with a clinical sample of participants from a different chronic health group condition and non-clinical sample would generate comparative and normative data, while test-retest reliability analyses would demonstrate whether or not the SSS is measuring a stable or transient experience of dermatological shame. It would also be useful to assess the sensitivity of the SSS to skin improvement

after intervention, via a longitudinal study. Further theoretically-driven research, including confirmatory factor analytic investigation of the 4 factors, would build on the model of dermatological shame and help establish the SSS as an appropriate and validated domain-specific instrument. Further testing and refinement of the SSS via confirmatory factor analysis might achieve this. Longitudinal studies might also investigate whether dermatology populations are likely to have high pre-morbid levels of shame-proneness or anxiety, in order to differentiate dermatological shame from characterological factors and to deliver the most appropriate interventions. This may also inform whether people whose skin aetiology includes psychological factors are more likely to experience psychological problems. The application of further qualitative research based on dermatological shame to people with skin conditions might be valuable in generating a more complete theory of skin distress. Like quantitative skin research, existing studies have been conducted largely without a theoretical grounding, or limited to a single diagnosis and the application of a rigorous methodology such as IPA or grounded theory might facilitate a better understanding of the personal experience of skin distress across conditions. This would help increase the involvement of patients at every stage of the research process, not only to enhance face validity, but also to increase user-involvement in line with current NICE directives.

## **5 PROCESS REFLECTIONS**

My overwhelming feeling about writing the thesis was of my difficulty discarding material that I had created and invested in emotionally. This process, though challenging, was facilitated by receiving joint feedback from my supervisors wherever possible, which minimized the time-consuming task of editing work according to an individual's personal style, then re-editing in response to another.

### **5.1 The profile of psychology and rise of the questionnaire**

What did strike me about this research process was the familiarity with which most participants engaged in the questionnaire process, many commenting that they had participated in studies with similar formats before. Many participants volunteered their ideas that the study was “about body image”, or “how your mind affects your skin”, which seemed to illustrate the increasing usage of psychological parlance in clinical, and perhaps, non-clinical populations. Whilst this usually appeared to enhance their engagement with the study, it should be noted that the participants' individual perceptions of what psychology is might also have primed them to generate a particular response set. It seems, however, to reflect the increasing awareness of psychological issues in healthcare settings and its salience within society in general, especially

perhaps, in the media. The expanding profile of psychology may have functioned as a means of normalizing contact with psychological services, so that it is less stigmatising, and patients are more willing to engage with it.

The proliferation of psychology notwithstanding, I was struck by the speed with which many participants engaged in describing their feelings about their skin. While this was occasionally difficult to manage within the framework of this quantitative study, it suggested that the need for dermatology patients, and likewise those with other chronic illnesses, to receive holistic psychodermatological healthcare, as recommended.

## **5.2 Supervision**

I feel incredibly blessed in terms of the research support I received throughout this project. Largely because my supervisors appeared to know what I needed as well as, and at times better, than I did. Their support ran the gamut of hypothesizing around tricky theoretical concepts to providing the containment and pastoral support that I needed. The faith of Dr Kellett and Dr Thompson in my abilities to both research and write allowed me to work independently but with the knowledge that no query was too naïve. Their ability to move up an intellectual gear stunned me on occasions but proved

invaluable and I felt reassured of their investment in the project. Being treated as a competent adult and colleague, as much as a trainee and amateur researcher, also allowed me to seek the type and level of feedback that I needed and to arrange deadlines with mutual respect. This illustrated the confidence factor, which I needed to conquer in order to produce the best thesis I could.

In short, this process was less aversive than I had feared, in part because it helped address my research-related fears. In spite of my fears of research burnout, I still feel interested in psychodermatology and keen to develop a dermatology-related position, which feels like an achievement. It is my hope that this study can play a part in contributing to the development of interventions that can challenge perceptions and alleviate skin distress and it is repeating this mantra (as a form of self-talk) that has kept me going. I don't perceive myself as a future research ace, but I never did before. I just hope that this project has been good enough and look forward to practicing clinically, as was my aim all along. Getting my life back seems like a pretty good outcome in the meantime.



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