Psychological aspects of Psoriasis

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Psychological Aspects of Psoriasis

by

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Declaration

The research contained in this thesis was carried out by the author between 1989 and 1992 while a postgraduate student in the Department of Psychology at the University of Durham. None of the work contained in this thesis has been submitted in candidature for any other degree.

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Abstract

Psoriasis is a skin condition characterised by raised, red, scaling patches that cover the body to varying degrees, with a prevalence of 1-3% in Caucasian populations. There is evidence that sufferers hospitalised for treatment of their psoriasis are more depressed and more anxious than controls (e.g. Fava *et al*, 1980; Lyketsos *et al*, 1985), but conflicting evidence about whether psoriasis outpatients are also more depressed and anxious. The research presented in this thesis examined depression and anxiety in a group of psoriasis outpatients and found statistically significantly higher depression and anxiety levels than in a group of matched controls. The relationship over time between area of coverage of psoriasis, depression and anxiety was examined in another group of psoriasis outpatients. Using multiple regression analysis, change in area of coverage between two assessments was a significant predictor of depression and anxiety at the second assessment, once levels at the first assessment had been accounted for. Self-esteem was also examined in this way and was found to be significantly related to psoriasis area of coverage, where worsening psoriasis was associated with a lowering of self-esteem. There were statistically significant differences between males and females.

Pain had not previously been examined systematically in psoriasis outpatients, but was higher than pain in matched controls in the first study reported in this thesis. Consequently the quality of pain was examined further, and found not only to be significantly related to psoriasis area of coverage, but also was described in terms which suggested a distinct character to psoriasis pain. Fluctuations in sleep quality were also found to be significantly associated with psoriasis area of coverage.

Visual assessment of psoriasis area of coverage was shown to be unreliable, so a computer program (SKINMAP) was developed to allow psoriasis lesions to be mapped onto a computer which then calculates area of coverage. SKINMAP estimates were shown to be statistically significantly more accurate and reliable than visual estimates.

Informal conversations with psoriasis sufferers suggested that they held firm views about their condition which often did not coincide with medical views. Lay beliefs about psoriasis in a group of sufferers were therefore investigated in detail. Sufferers showed quite high levels of knowledge about the condition, but the nature of some common misconceptions was investigated through the use of semi-structured interviews, and the results highlighted the need for better patient education.

Dedication

To Angie
who makes all things possible

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Thanks to my parents for their encouragement and interest, and for their support when times were hard as well as their joy when things went well. Thanks are due also to Simon Jacob, whose artistic talents were invaluable in the early stages of SKINMAP screen development.

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Chapter One

Introduction and Literature Review

1.1 **Introduction**

The aim of the research presented in this thesis is threefold. First, to examine the link between disease severity and mood in psoriasis sufferers; in particular, to assess depression, anxiety and self-esteem and to determine whether they vary as the area of coverage of psoriasis fluctuates. Second, to develop and validate a computer-aided assessment technique for determining the area of coverage of psoriasis. And third, to examine sufferers' beliefs and knowledge about psoriasis, their perceptions of the nature of their disease and its treatment, and their expectations for its likely prognosis.

1.2 **Psoriasis as a physical illness**

Psoriasis is a skin condition characterised by discoid, raised, red, scaly patches. Until the early nineteenth century psoriasis was taken to be a form of leprosy: even when Robert Willan in 1809 described for the first time different manifestations of psoriasis, he did not define them in terms of a disease completely separate from leprosy. It was not until 1841 (Farber, 1991) that psoriasis was described as a disease *sui generis*.

1.2.1 **Clinical features**

The psoriatic lesion is sharply defined (i.e. with no gradual change from unaffected to affected skin) and may vary from pinpoint size to several inches in diameter. Lesions tend to be asymmetrically distributed on the body in the early stages of the condition but the pattern becomes more symmetrical as the disease progresses (Farber & Nall, 1974): in extreme cases it may completely cover the whole body (*erythrodermic psoriasis*). The outline shape of large lesions is polycyclic, indicative of the fact that small lesions tend to expand and combine to form larger plaques. Typically, the patient presents with some areas of the body affected and some areas clear. The most commonly affected areas are the elbows, knees, and scalp (Lomholt, 1963).

There are three common types of psoriasis. They are quite different in appearance, but possess the common features of erythema, thickening and scaling. Different manifestations may be present at the same time in one patient, although this is uncommon, and different manifestations may appear at different times during a patient's life: even within one episode, clinical signs tend to vary considerably as the disease progresses (Mier & van de Kerkhof, 1986).

Different manifestations of psoriasis are characterised by the size and distribution of the lesions. If they are small and widely distributed, the condition is diagnosed *guttate psoriasis*, whereas if the typical lesion is larger (coin size to palm size), the diagnosis is

chronic plaque psoriasis. If the lesions are characterised by pustules, the label *pustular psoriasis* is appropriate. Other manifestations exist, but their prevalence is low. The most common form is chronic plaque psoriasis which accounts for approximately 90% of adult psoriasis cases (Mier & van de Kerkhof, 1986).

Psoriasis also often affects the nails with pitting and brown discolouration. There are no significant differences in the degree to which nails are affected between different manifestations of the condition (Calvert, Smith & Well; 1963). Joints may be affected (*psoriatic arthropathy*), and may even be affected in the absence of any cutaneous manifestation. Psoriasis of the nails is much more prevalent (Wright, 1957) in patients with psoriatic arthropathy (87%) than in patients with only cutaneous involvement (15–18%).

Once the patient has psoriasis, its course is variable and may last from a few weeks to several decades. Farber & Nall (1983), for example, summarise the data in five studies which looked at length of suffering and the number and duration of remissions. These data are presented in Table 1.1. About half the patients reported at least one period of remission at some point.

TABLE 1.1 Reported time since onset of psoriasis, and the frequency and duration of remissions in five studies

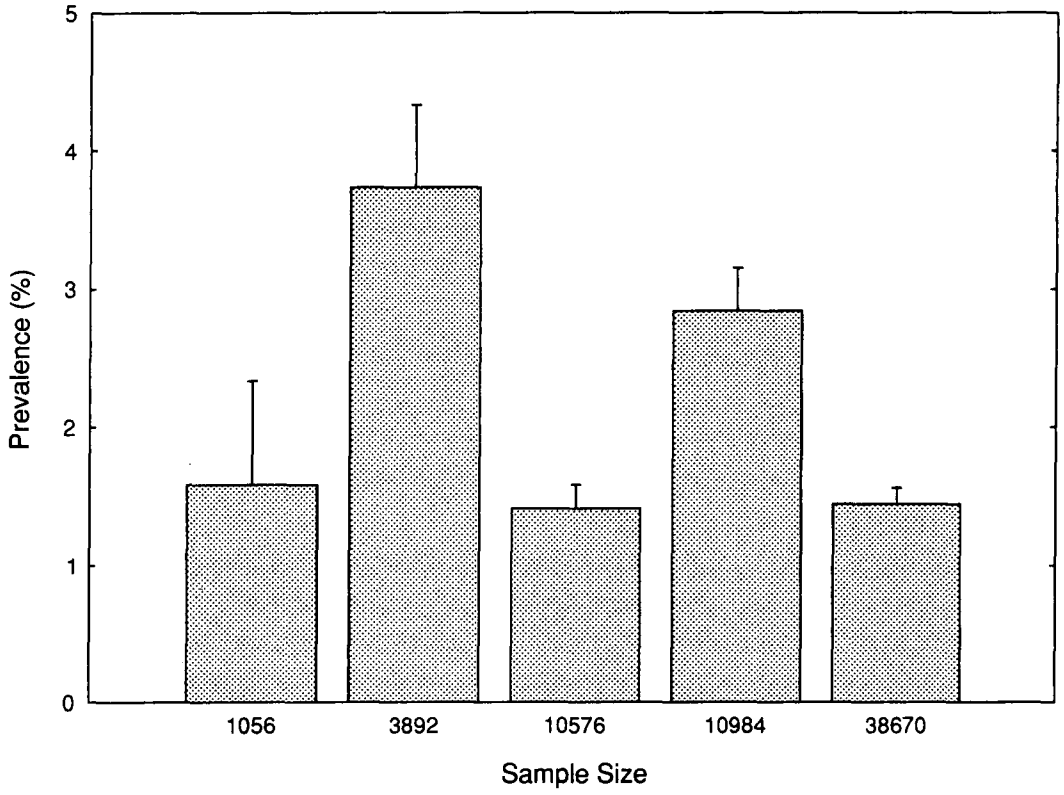
Location	*Time since onset (years)*	*% reporting remission*	*Mean length of remission (months)*
Denmark	19	55	35
United States	17	41	46
Sri Lanka	8	46	22
Hong Kong	7	36	9
Kuwait	7	42	18

To summarise, psoriasis is a skin condition which may take various forms and cover different parts of the body: it may also affect the nails and joints. Once a person has psoriasis it may last for many years, but patients can experience remissions during its course.

1.2.2 **Epidemiology**

While several studies have attempted to assess the prevalence of psoriasis in other countries, only one (Rea *et al*, 1976) has focussed specifically on Britain. Rea and his colleagues found a point prevalence of 1.58% in a random sample of 1056 individuals

Figure 1.1 Estimated psoriasis prevalence rates and 95% confidence intervals



in North Lambeth, London. This is broadly in line with point prevalence figures reported for other primarily Caucasian countries. For example, Braathen, Botten & Bjerkedal (1989) reported a prevalence of 1.41% in Norway, Hellgren (1967), in an extensive epidemiological study in Sweden found a prevalence for definite psoriasis of 1.44%, while Lomholt (1964) in the Faroe Islands reported a prevalence of 2.84%. Brandrup and Green (1981) found a prevalence of 3.73% in a random sample of Danes, but this was a lifetime, rather than a point prevalence. These prevalence estimates are shown graphically with their 95% confidence intervals in Figure 1.1.

All point estimates would therefore put the prevalence of psoriasis in Caucasian populations at between 1% and 3%; one lifetime prevalence rate was 3.7%.

The data for prevalence rates by sex, however, are less clear. Most general texts on dermatology (e.g. Rook, Wilkinson & Ebling, 1986) or psoriasis (e.g. Mier & van de Kerkhof, 1986) suggest that there is no difference between the prevalence in men and in women. Examination of the data does not wholly support this.

The data for the five studies are shown in Table 1.2. We can compare the differences between the proportions - the so-called effect sizes denoted d′ - which is approximately distributed as χ^2 with k-1 degrees of freedom, where k is the number of studies (Rosenthal, 1984).

TABLE 1.2 Prevalence of psoriasis by sex, reported in five epidemiological studies.

	Males			Females		
Country	N	Psoriatic	Prevalence	N	Psoriatic	Prevalence
England	-	-	.0258	-	-	.0077
Denmark	1916	80	.0418	1976	65	.0329
Norway	5122	70	.0137	5454	79	.0145
Faroe Islands	5536	158	.0285	5448	154	.0283
Sweden	20569	473	.0230	19002	285	.0150

The value for χ^2 is 13.91 with df=4, which is significant at the 0.003 level. The results are therefore significantly heterogeneous and cannot be pooled for an overall analysis. Examination of the rates in Table 1.2 however shows that epidemiological studies generally find more men with psoriasis than women. This is not a consulting effect (i.e. it is not simply that more males consult doctors for psoriasis) since the data comes from epidemiological studies sampling general populations, not from clinical records. Indeed, Hellgren (1967) found that psoriasis was more prevalent in males in all geographical areas even when age and occupational status had been controlled for.

To summarise, therefore, the point prevalence of psoriasis is between 1% and 3% in Caucasian population, and the prevalence for males is slightly higher than for females.

1.3 Psoriasis as a psychosomatic illness

Psoriasis is often classified as a psychosomatic illness (e.g. Blake, 1987; Dorfman & Cristofar, 1985). If it is to be referred to in these terms some definition of the concept of a psychosomatic illness must be provided.

Some physical illnesses appear to be more susceptible to psychological influences than others, and the term "psychosomatic" can be used to describe them. The term "psychosomatic illness" refers to those conditions in which emotional or psychological factors lead to somatic reactions: the term does not apply when psychological reactions are caused by illness (Whitlock, 1976). This definition includes cases where emotional factors help cause a physical condition, as well as where they influence the course of a

condition. There is one important caveat: the term psychosomatic does *not* apply when emotional disturbance and physical condition simply co-exist. A causal link, or at least a suspected causal link is necessary for denoting a physical illness as "psychosomatic".

1.3.1 **Psychosomatic skin diseases**

Over the past four or five decades definitions of what constitutes a psychosomatic skin disease have changed. Alexander (1943), for example, developed a classification system which attributed to specific conditions, specific emotional disturbances. However, this so-called "specificity hypothesis" has now been largely superseded: partly because Alexander's (and other's) work tended to rely on psychoanalytic case studies in which there were seldom adequate controls, and partly because the conception of a multifactoral origin to disease in general has tended to move medical thinking away from searching for unidimensional causes for conditions. Several other authors, notably Wittkower & Russell (1953) and Obermayer (1955) attempted to devise classification systems that would delimit the extent to which psychological factors influenced the onset and course of cutaneous diseases. A more general approach is usually taken today. Rook, Wilkinson & Ebling (1972), for example, have distilled a wide range of classification systems into five categories:

1) Conditions exclusively emotional in origin - e.g. *dermatitis artefacta.*
2) Conditions of other origin which are aggravated or perpetuated by self-inflicted trauma, e.g. *acne excoree.*
3) Conditions which are provoked or perpetuated by demonstrable psychosomatic factors, e.g. *hyperhidrosis.*
4) Conditions in which psychological factors are frequently implicated as predisposing or perpetuating factors, e.g. *urticaria.*
5) Conditions which are sometimes influenced by psychological factors, e.g. *vitiligo.*

These distinctions are primarily concerned with the extent to which psychological factors influence the onset or course of a cutaneous condition. They are merely a classification system: they do not add anything to our understanding of the underlying mechanisms of disease pathology or perpetuation. Nevertheless, they do serve to highlight the fact that different skin conditions can be affected in different ways by emotional factors. Psoriasis falls into either category 4 or 5 of this classification system.

1.4 **Psychiatric morbidity and psoriasis**

Hughes, Barraclough, Hamblin & White (1983) set out to discover whether patients attending a dermatology clinic showed a higher prevalence of psychiatric disorder than

the general population. They administered the 30-item General Health Questionnaire (GHQ-30) to 196 outpatients and 40 in-patients, chosen consecutively from new referrals. A cutoff point of 5 was used to indicate a possible "case", and those individuals who attained this score were given the Wakefield Self-Assessment Depression Scale (WSADS), and interviewed about their perceptions of the relationship between psychiatric symptoms and their skin condition. The cutoff point on the WSADS for probable depression is 14.

Thirty percent of the outpatient group exceeded the GHQ-30 cutoff score, as did 60% of the in-patients. Of these, 49% of the outpatients and 54% of the in-patients scored above the cutoff point on the WSADS. The numbers of males and females that are represented in these figures were not reported. The authors compared these results with those of Goldberg (1976) who reported 11% of 213 individuals taken from the general population and 30% of 365 General Practice patients scoring above the cutoff point. Thus, the dermatology outpatients had similar scores to those of general practice outpatients, and both dermatology and general practice outpatient groups scored higher than figures reported for the general population. However, more dermatology in-patients in Hughes' *et al* study scored above the cutoff point than has been found in studies using samples of general medical in-patients (e.g. McGuire *et al*, 1974, found 33% of 230 general medical in-patients could be classified as cases).

This study is of particular interest because the authors also examine how the psychiatric symptoms and skin diseases might be linked by reference to four categories of psychosomatic influence, as follows:

1) Self-reports of psychiatric symptoms pre-dating or exacerbating the skin condition were found in 28% of the probable cases. The authors note that these patients did not have any particular subset of illnesses. It is not possible to conclude from this sort of data that the psychiatric problem precipitated changes in the skin condition. A prospective methodology together with clinical assessment of psychiatric symptoms would be required to detect a true temporal relationship.

2) The second possibility that the authors examined was a psychiatric disorder whose symptoms are in the form of skin lesions. Three of the "cases" fell into this category: two with hypochondriacal preoccupation with trivial lesions and one with *dermatitis artefacta* (self-mutilation).

3) The hypothesis that the stigma of having unsightly lesions on exposed parts of the body might lead to psychiatric problems was addressed by examining the type and location of the skin condition. Forty seven patients had conditions which affected the face or hands, and of these, 70% scored above the cutoff point on the GHQ-30. With the exception of *dermatitis artefacta*, the chronic conditions which affected wide-spread areas of the body (e.g. *psoriasis*) or conditions which affected only the visible parts of the body (e.g. *alopecia*) showed the highest GHQ-30 scores (see Table 1.3).

Table 1.3 GHQ scores reported by Hughes *et al* (1983) for a range of skin conditions

Condition	*N*	*% GHQ ≥ 5*	*Mean GHQ*
Dermatitis artefacta	1	100	20
Alopecia	4	75	12
Widespread lesions present for > 6 weeks (e.g. psoriasis)	125	46	7
No lesion (e.g. pruritus)	11	27	3
Small non-malignant single lesions	63	14	3
Small malignant single lesions	23	8	2
Widespread lesions present for < 6 weeks	7	0	2
Systemic lymphoma	2	0	3

4) One further possibility was examined: that drugs used to treat the skin condition may also cause psychiatric effects. Steroids, for example, used topically for skin conditions can have psychiatric side-effects if used in high doses (Lewis & Smith, 1983). The patients on high-dose steroids in this study did score above the GHQ-30 cutoff point more often than others, but this is probably confounded by the fact that high dose steroids were being used by those patients with the most severe skin conditions.

This study by Hughes *et al* has therefore suggested that there are more dermatology outpatients exceeding the level set for possible cases on the GHQ-30 than are found in the general population. It has also suggested that those conditions which are chronic or visible in normal situations, tend to contribute to greater numbers of cases.

Wessely & Lewis (1989), while accepting the broad findings of Hughes *et al*, suggest that the impact on a patient's life is more important in predicting psychiatric morbidity than the location or severity of skin lesions. They used two measures of psychiatric

morbidity: the GHQ-12 (cutoff point 2), and the Clinical Interview Schedule (CIS - cutoff point 13). In 160 subjects from a sample of 173 consecutive outpatients, they found 40% cases defined by CIS scores, with women scoring non-significantly higher than men (mean for males 12.1, females 13.4). The GHQ-12 revealed 43% cases. While the authors do not give any indication of the numbers of subjects suffering from individual conditions (11 skin conditions were represented in the group), they note that no significant difference was found on CIS scores between illnesses. This is interesting in the light of Hughes' findings (above). Wessely & Lewis's sample comprised individuals with warts, single lesions and nævi, as well as conditions more widespread, chronic and visible, such as psoriasis, alopecia and acne. Hughes' findings would suggest that there should be more cases in this latter group than in the former. Wessely & Lewis did find, however, that area of coverage on exposed regions of the body was positively correlated with a self-report measure of how much impact the skin condition had on patients lives, as was time since onset, but not total area of coverage. This "impact" measure was in turn highly correlated with the CIS scores.

Wessely & Lewis suggest, therefore, that any psychiatric morbidity in dermatology patients is of a general nature and due more to the perceived impact on the patients lives, in terms of the behaviour modification that is entailed, than to the location or distribution of the lesions, or to the specific condition. The fact remains, however, that those conditions which were reported to have the highest impact on the patients' lives were more likely to be chronic conditions with more visible lesions.

To summarise, studies which assess the prevalence of psychiatric morbidity in dermatology patients have found higher levels of cases than in the general population. The rate is much higher in hospitalised dermatology patients whose rates are in turn higher than in hospitalised general medical patients.

1.5 **Psychological variables associated with psoriasis**

Investigations into the psychological concomitants of psoriasis fall broadly into two areas: 1) studies which have assessed effects of psoriasis on patients' lives in general, and 2) studies which have attempted to quantify specific psychological variables. Within these categories, different researchers have employed varying methods and while many of the results overlap, it is useful in the first instance to examine them in their individual categories.

1.5.1 **Reported effects of psoriasis on the patient's life**

Jobling (1976) surveyed 291 members of the British Psoriasis Association by postal questionnaire regarding their psoriasis. Multiple answers to each question were allowed and the questions were open-ended, not multi-choice. Eighty four percent said that one of the worst things about having psoriasis was establishing social contacts and relationships, while 25% reported the worst aspect to be suffering embarrassment and shame about their condition. Sixteen percent were very concerned about being stared at by other people, and 20% felt the worst aspect of psoriasis was having to wear particular types of clothing in order to cover affected areas. The problem of bias arising from restricting the sample to members of the psoriasis association cannot be overlooked when interpreting these results, but it seems clear that the appearance of the condition and the reactions it elicits from other people are major concerns.

Approaching this idea from a slightly different perspective, Baughman & Sobel (1970) set out to devise a self-report measure of psoriasis severity. They had psoriasis sufferers and dermatologists rate on a seven point scale 50 features of psoriasis according to the degree to which each feature "indicates the severity of this disease". Selecting 23 of the items for their final scale, they found that, while dermatologists ranked "Embarrassment over appearance" as the *least* important indicator of severity, the patients ranked it the *most* important.

Stankler (1981) extending Jobling's line of enquiry to a more representative sample questioned 100 consecutive outpatients about what they considered the worst aspect of psoriasis. Again with an open-ended question, 87% of his sample reported that the worst aspect of psoriasis was feeling embarrassed about the condition, particularly when it affected visible parts of the body, or regions that became visible under certain circumstances (e.g. sports or work). Males reported largely the same problems as females. This was in contrast to the findings of a previous study by Roenigk & Roenigk (1978) who had reported significant differences between males and females in the degree to which their "relations with the same sex" were affected and the degree to which they were affected by "worry and stress", with females reporting more problems than males.

Noting that much of the research into the social consequences of psoriasis (and skin disease in general) had been "presented in an anecdotal and unstructured way", Jowett & Ryan (1985) interviewed 100 outpatients (at their own homes) about the consequences and experiences with their skin condition. Their sample comprised 32% with eczema, 38% with psoriasis and 30% with acne, and in each group the condition affect-

ed either the hands or the face in 84%, 83% and 81% of cases respectively. One criterion for inclusion in the sample was a time since onset of twelve months or longer. The mean time since onset in the psoriasis group was 13 years.

Jowett & Ryan asked sufferers what they thought was the worst aspect of having psoriasis, and reported that "the majority" said it was embarrassment caused by the appearance of the lesions, together with awareness of other peoples' reactions. Furthermore, while 38% reported experiencing no difficulty at work through their psoriasis, 15% did say they felt that their employment opportunities were limited because they had psoriasis, and 44% reported that they had experienced functional difficulties at work because of their condition. Four subjects suffering from psoriasis or eczema said they had had to leave their job because of their condition, and others reported that chemicals at work irritated their lesions.

Their interview schedule also included systematic inquiries about the negative emotions that patients felt because of their condition. Not only did psoriasis sufferers think that, in general, embarrassment was the worst aspect of psoriasis, 89% of them reported actually feeling embarrassment or guilt because of their condition.

These findings were broadly supported by Dooley & Finlay (1990) in 35 psoriasis outpatients using repertory grid technique. In comparison with a control group of 28 other dermatology outpatients and a further group of 29 members of the general population, they found that the psoriasis group was least well socially adjusted on their embarrassment construct (a low score for social adjustment on this construct corresponded to a high level of embarrassment in social situations) with a mean score of 89.2, compared to a mean of 106.8 for the other dermatology group and 96.8 for the non-dermatology controls. The difference between groups was significant, but this was accounted for by the difference between the psoriasis group and the dermatology controls. Further, when these results were analysed by sex, there was no difference between males in the three groups, but females reported more embarrassment in social situations than either control group: again the significant difference was between the psoriasis group and dermatology controls.

Taken together, these studies suggest that psoriasis sufferers are highly embarrassed by their condition, and those feelings of embarrassment may be heightened in social situations. They may also experience impairment in their relationships with other people, and a minority feel that their employment chances are limited because of their psoriasis.

Given the existence of these feelings of embarrassment, guilt and shame, it is pertinent to enquire how psoriasis affects the self-esteem of sufferers, and some limited research has attempted to examine this area. However, Wells and Marwell (1976) have demonstrated that self-esteem research has been hampered by inadequate definition, so this must be clarified before examining the findings that relate specifically to psoriasis.

1.5.2 **Self-esteem**

In research on self esteem the view most commonly accepted has, until recently, resulted in the measurement of self esteem as a global construct (e.g. Rosenberg, 1965): and because of this relatively unsophisticated view, the development of measuring instruments has been largely unsatisfactory (Bingham, 1983; Marx & Winne, 1980; Watkins, 1978). Over recent years however, self-esteem has more usefully been conceptualised as several different dimensions (Fleming & Courtney, 1984; Marsh & Shavelson, 1985; Robson, 1988), and measuring instruments now tend to reflect these dimensions, while still retaining an assessment of global self esteem.

Building on his comprehensive review of the literature (Robson, 1988), Robson (1989) has defined self esteem in a way which overcomes some of the shortcomings of the "conceptually primitive" definitions previously employed. He combined the work of Rosenberg (1965), who concentrated on the relationship of self esteem to the sense of personal worthiness held by an individual, the evaluation of their appearance, and their level of social confidence, with that of Coopersmith (1967), who highlighted the importance to self esteem of feelings of competence and power, and Beck (1967), who noted that the way an individual interprets events partly determines the view the individual has of the self.

Following Robson then, self-esteem in the present study is defined as:

> The sense of contentment and self acceptance that results from a person's appraisal of their own worth, significance, attractiveness, competence and ability to satisfy their aspirations.
>
> (Robson, 1988, p.13)

The important theoretical advance in this conceptualisation is that the concept of *global* self-esteem is retained while the individual components of which it is comprised are also recognised. Marsh & Shavelson (1985) and Marsh (1986) have suggested that self-esteem ought to be measured as a situation-specific variable: one's self-esteem only has relevance as a concept if the situational factors are taken into account. Thus, Marsh's approach has been to develop a measure of self esteem that inquires about feelings in a range of specific situations. The problem with this approach is defining sufficient

numbers of situations about which to inquire. A self-esteem instrument following Marsh's conception would require a large number of questions, and the notion of self-esteem as a global measure would be lost.

1.5.2.1 **Self-esteem and psoriasis**

In one of the most thorough investigations into the effects of psoriasis on the sufferer, Ginsburg & Link (1989) examined feelings of stigmatisation associated with the condition. They defined *stigma* as "a biologic or social mark that sets a person off from others, is discrediting, and disrupts interactions with others", and devised a questionnaire to evaluate feelings of stigmatisation. Following administration to 100 adult psoriasis sufferers, factor analysis revealed six main dimensions of the stigma experience: anticipation of rejection (fear of how others might react to the condition), feeling flawed (feelings of weakness and dirtiness), sensitivity to others' opinions (reactions to *actual* behaviour of others), guilt and shame (falling short of one's ideal image, guilt over passing psoriasis to children), positive attitudes (taking a positive view of the consequences of the condition), and secretiveness (attempting to conceal the condition). One overall category was also identified and labelled psoriasis-related despair, which composed items that loaded on all factors.

Age at onset was a significant predictor of all factors except feeling flawed: the direction of prediction was the same in all cases (i.e. the older the patient was when the condition first appeared, the lower the patient's score). Also, the longer a patient had had psoriasis the less guilt and shame they exhibited and the less secretive they were. The best predictor of feelings of stigmatisation among disease symptoms was the extent of bleeding, but interestingly neither area of coverage nor visibility of the lesions accounted for any significant amount of variance. Ginsburg & Link note that, for each of their stigma factors, the predictors they identified accounted for between 11 and 30% of the variance, and suggest therefore that other processes are involved in coping with feelings of stigmatisation, such as learnt coping strategies or social support networks.

This paper on feelings of stigmatisation in psoriasis has considerable bearing on self esteem. Many of the questions in their instrument coincide with those appearing on self esteem measures. For example, the question with the highest loading on the factor *anticipation of rejection* was "When my psoriasis improves after intensive treatment, I feel much better about myself". Self-evaluative statements such as this link closely with the concepts of self esteem: 46% of their sample strongly agreed with this item.

To summarise, studies which have investigated how psoriasis sufferers feel about their condition and how it affects their relationships with other people have found that they report feeling very embarrassed and guilty about their appearance, and report some reduction in opportunity and interpersonal contact because of their condition. Feelings of stigmatisation are apparent in psoriasis sufferers, which are related to the age at onset and the time since onset of the condition, and the amount of bleeding involved.

These findings can be related to more theoretical conceptions of psychopathology. Following the work of Lewinsohn's group, (e.g. Lewinsohn, 1974), several studies have suggested that symptoms of depression are more likely to occur in individuals who do not have access to social situations where they can receive positive reinforcement (e.g. Brown & Harris, 1978). This applies to individuals with stigmatising marks. Goffman (1968) hypothesised that the non-stigmatised will tend to avoid entering long-term relations with stigmatised individuals because they tend to be associated with the same negative social connotations. Empirically, this has been examined by Kleck, Ono & Hastorf (1966) who found that in face-to-face interactions with stigmatised individuals (the stigma in this case was a bogus left-leg amputation) subjects tended to terminate interactions significantly quicker than when interacting with a non-stigmatised individual.

This would tend to suggest that one consequence of feeling stigmatised for dermatology patients may be raised levels of depression brought about by decreased positive interpersonal contact, and a subsequent lack of positive reinforcement. Depression in psoriasis sufferers is reviewed below.

1.5.3 **Depression**

The term depression has come to mean different things in different contexts. To the psychiatrist or clinical psychologist depression is a generic term which can be subclassified into specific conditions with clearly defined criteria and symptomatology. To the general practitioner, the word depression may have a somewhat less stringent definition, and to the patient, depression may simply refer to depressed mood, or feelings of sadness.

DSM-111-R characterises the essential features of depression as either persistent depressed mood, or persistent loss of interest in all (or almost all) activities. Associated symptoms are disturbance in appetite (often resulting in deviations from normal weight), disturbance in normal sleep patterns, persistent feelings of restlessness or slowing down, uncharacteristic fatigue, inappropriate feelings of worthlessness or guilt,

reduction in the ability to concentrate, and recurrent thoughts of death or suicide (American Psychiatric Association, 1987). DSM-111-R lists chronic physical illness as a predisposing factor for a major depressive episode, and further notes that a major depressive episode may be "...a psychological reaction to the functional impairment associated with a physical illness that does not involve the central nervous system...". Psoriasis is a chronic physical illness and as such may predispose sufferers to an increased risk of depression. To assess the magnitude of this increased risk, it is useful first to examine rates of depression in the general population and in the physically ill in general.

1.5.3.1 **Depression in the general population**

There is some disagreement on the prevalence of depression in different populations, partly because different researchers choose to define depression using different criteria. Hall, Beresford & Blow (1987) note that the DSM-111 classification Organic Affective Syndrome which has been used for some research, is inadequate because it excludes those individuals whose depression co-exists with other states such as cognitive impairment, yet the criteria for inclusion are broad enough to encompass physical symptoms which may parallel those of depression, but which are due to a somatic disorder, e.g. weight loss and insomnia. This criticism can also be applied to the preferred assessment instruments for detecting depression, in that they most usually focus on somatic symptoms which may reflect physical conditions rather than dysthymic states. Indeed, Snaith (1987) pointed out that 42% of items on the Hamilton Depression Scale examine physical symptoms that often relate solely to physical illness, and noted that other rating scales tend to follow the same pattern. He suggests that anhedonia (the inability to experience pleasure) is the most central indicator of depression. Problems with the measurement of the incidence and prevalence of depression are further compounded because population characteristics tend to vary by geographical location (areas with predominantly middle class residents, for example, show lower depression rates than those with lower class residents, e.g. Brown & Harris, 1978).

With these restrictions in mind, Weissman & Myers (1978), for example, report that between 10 and 16% of males and between 20 and 24% of females in a variety of general population samples produce high scores on self-report depression measures. Classification using the Present State Examination (PSE), however, has suggested lower rates: 2.6% males, 6.7% females (Henderson *et al* 1979); 3.9% males and 7.4% females (Wing 1980).

1.5.3.2 **Depression and physical illness**

Similar problems apply to assessing depression in general medical patients. One reviewer noted that estimates of the prevalence of depression in medical patients varied between 5% and 58% (Hall, Beresford & Blow, 1987). There is however, evidence that depression and physical illness tend to co-exist, particularly when the illness is chronic or severe. Stewart, Drake & Winokur (1965), for example, found that 27% of severely ill in-patients were suffering from depression compared with 13% of those diagnosed as moderately to mildly ill. Moffic & Paykel (1975) estimated these prevalence rates to be 61% and 21% respectively in their sample.

The relationship between depression and physical illness depends on several factors. The physical illness itself may stimulate the body to produce chemicals which affect emotional states: excess ACTH secretion by the pituitary gland in Cushing's disease, for example, is associated with a high incidence of depression (Smith, Barrish & Correa, 1972). The treatment for a somatic condition may affect emotional states: Schoonover (1977), for example, has suggested that steroids may cause depression. The stress of day-to-day coping with chronic illness may also affect emotional states. On the other hand, depression may also affect the individual's ability to control their disease: depressed mood and concomitant lowering of motivation may affect compliance with treatment regimens, which in turn lead to a worsening of the condition.

To summarise, while estimates vary because of differing definitions, prevalence of depression in the physically ill is higher than in the general population.

1.5.3.3 **Depression and psoriasis**

Several authors have investigated the link between psoriasis and depression. Results have been inconsistent, but some important findings have been reported.

One of the earliest studies that attempted to isolate psychological characteristics of psoriasis sufferers administered the Maudsley Personality Inventory (MPI) and the Minnesota Multiphasic Personality Inventory (MMPI) to 13 consecutively admitted psoriasis in-patients and 13 control in-patients not suffering from chronic skin conditions (Goldsmith, Fisher & Wacks, 1969). Tests were supplemented by a psychiatric interview. Psoriasis sufferers did score higher than controls on the Neuroticism scale of the MPI, but both groups were within the range defined as "normal". The results of the MMPI were more complex. There was no statistically significant difference between the mean depression scores of the two groups, but interestingly the psoriasis group's mean (76.5) was above the level usually taken as indicating psychopathology (Anastasi,

1988): that is, the scales are standardised to have a mean of 50 and a standard deviation of 10 (usually referred to as *T*-scores), and a cutoff point of mean plus two standard deviations is used. The control group's mean was below this cutoff point (66.9).

There was, however, a statistically significant difference between groups on the Hysteria scale (psoriatic mean 71.2, control 60.5) and the Psychasthenia scale (69.5, 55.6). Hysteria, in the context of the MMPI scale, refers to a preoccupation with physical symptoms, but usually associated with a marked *lack* of depression or anxiety. Psychasthenia on the other hand is taken to be associated with low self-esteem, which would tend to support the depression scores.

The MMPI was also used (in combination with the California Personality Inventory - CPI) by Gilbert, Rodgers & Roenigk (1973) on a slightly larger sample of hospitalised psoriasis patients. Fifty consecutive in-patients were compared with two control groups: 15 psoriasis outpatients and 15 dermatology in-patients not suffering from psoriasis. No statistically significant differences were found between the groups on the MMPI, although the hospitalised groups scored slightly higher than the outpatients on all scales. The authors explained the discrepancy between their findings and those of Goldsmith *et al* in terms of a larger sample size. This is not altogether convincing. It is equally possible that the samples were not comparable. Indeed, while little data are reported on the composition of Gilbert's psoriasis in-patient sample (the numbers of males and females are not given, for example), it is noted that three of the group were in fact clear of psoriasis and hospitalised only for liver biopsies (following methotrexate therapy).

Gilbert's CPI results suggested that the hospitalised psoriasis patients exhibit lower social comfort, confidence, enthusiasm and commitment than the outpatients and the non-psoriasis in-patients. They interpret this as resulting in "sustained emotional tension" which may be associated with secondary psychological problems. They do not enlarge on these alleged problems.

This area was examined further by Fava *et al* (1980) in their study of psychological distress in patients suffering from psoriasis, urticaria and fungal infections. Once again using in-patients (n=20 in each group), Fava *et al* used the 30-item Kellner-Sheffield Symptom Rating Test (SRT) to detect depression, anxiety, somatisation and inadequacy. They found a significant difference in total SRT scores between the psoriasis group (mean 18.5) and the fungal infection (11.0) group, and between the urticaria group (22.3) and the fungal infection group. The fungal infection group scored close to the reported cultural mean of 11.9. On the subscale that measures depression, the psoriasis

group had a mean of 0.52, the urticaria group 0.72, and the fungal infections group 0.28. The difference between the groups was statistically significant. These findings suggest that hospitalised psoriasis patients have raised levels of depression which are not matched by patients with dermatologic conditions that are not thought to have a "psychosomatic" associations.

Lyketsos *et al* (1985) also used urticaria (n=28) as a control condition for psoriasis (n=26), and included alopecia as a third condition (n=26): all groups were again in-patients, as were a group of "non-psychosomatic" controls (n=38). Using the States of Anxiety and Depression Scale (SADS) they found that the psoriasis group scored very significantly higher than the non-psychosomatic controls on depression (psoriasis mean 5.7, control mean 0.4). Furthermore, they found 73% occurrence of "simple depression" on the Present State Examination in the psoriasis group, compared with 18% in the control group. These data suggest that psoriasis in in-patients is associated with raised levels of depression.

Perhaps of more interest though, are the findings of Hardy & Cotterill (1982) who examined depression in a small sample of dysmorphophobics and psoriasis outpatients, rather than those hospitalised for their condition. Unfortunately their sample of dysmorphophobics comprised mostly women (twelve out of fourteen), and their psoriasis group and a control group drawn from the general population were matched for sex. Further, one member of the psoriasis group was in fact hospitalised for psoriasis therapy. Nevertheless, Hardy & Cotterill found significant differences between groups on the Beck Depression Inventory (BDI). The dysmorphophobic group had the highest depression scores (mean 15.4), followed by the psoriasis group (9.1) and the controls (3.9). The psoriasis group's mean BDI score of 9.1 is borderline for minimal/mild depression (a cutoff score of 10 can be taken as the lower limit for probable mild depression; Beck, Steer & Garbin, 1988). This would suggest that psoriasis sufferers *not* hospitalised for their condition may have raised, but not clinically severe levels of depression.

None of the studies reported above have examined the severity of psoriasis as an independent variable. Gupta *et al* (1991) have examined the link between depression and psoriasis in more detail. This study has certain advantages over the many others in that it was a prospective study, evaluating symptoms of depression and disease severity over a period of a few weeks (the mean stay in hospital was 23.1 days), and in the Gupta study psoriasis was the only condition examined. It does, however have some limitations. The sample was drawn from a hospitalised population, who might be expected to have raised levels of depression *whatever* their condition (e.g. McGuire *et al*, 1974).

Further, it is not reported how the measure of psoriasis severity, percent Total Body Surface Area covered, was arrived at (this point will be discussed in more detail in Chapter 2).

Nevertheless, Gupta's findings are interesting. He split 95 in-patients into three groups by the degree of response to therapy: low, moderate, and high. The changes in scores on the Carroll Rating Scale for Depression are given in Table 1.4. While there was no statistically significant difference between the pre-treatment levels of depression, there was a significant difference between the post-treatment scores. So while depression was not related to pre-treatment severity, it was related to the degree to which the psoriasis cleared. Gupta does not report the location of lesions (i.e. whether or not they fall mainly on visible areas), but the likelihood is that the psoriasis would be fairly generalised to warrant hospitalisation. These findings suggest that depression may be more easy to detect in patients with severe psoriasis than in those whose condition is relatively mild.

TABLE 1.4 Change in depression scores with change in psoriasis severity. Scores given are means and standard deviations (from Gupta *et al*, 1991)

Effectiveness of Treatment	*Initial depression scores*	*Change in depression scores*
Low	13.2 (±10.5)	3.6 (±5.8)
Medium	13.6 (±7.7)	4.5 (±4.3)
High	15.1 (±7.9)	7.6 (±7.2)

More recently Price, Mottahedin & Mayo (1991) have investigated the effects of stress reduction techniques on the course of psoriasis and on depression, anxiety (see below) and self-esteem. One group of 11 subjects attended eight therapy sessions, another group of 12 patients acted as controls. They were assessed three times for levels of anxiety and depression on the Hospital Anxiety and Depression Scale (HADS) and for self-esteem using an eight-item scale devised by O'Malley & Bachman (1979). The first assessment was prior to any group sessions, the second after an 8 week course of group therapy, and the third at a six month follow-up. Psoriasis severity was rated on a visual analogue scale completed by the patient and the dermatologist. The patients in this study on the whole scored low on the depression scale of the HADS, but there was a decrease in depression scores in the therapy group from 4.0 to 3.1 which was not matched in the control group (4.1 to 4.8).

To summarise, in general psoriasis inpatients have raised levels of depression, but the evidence for raised levels of depression in psoriasis outpatients is inconclusive, and the depression reported does not reach clinical levels. Two studies have shown that that the level of depression tends to vary as the disease varies.

1.5.4 **Anxiety**

Anxiety is a normal emotional reaction to everyday stimuli. It is not the presence or absence of anxiety reactions *per se* that is clinically important, rather it is the severity of those reactions and the frequency of their occurrence that is of interest.

Izard (1972) proposes that anxiety can be thought of as a combination of emotions; the fundamental emotion of fear, plus two or more of distress, shame, anger and interest-excitement. In Izard's formulation, anxiety is composed of three components: neuro-physiological, behavioural-expressive, and subjective. The neurophysiological component is indicated by the physical changes that accompany anxiety: raised heart rate and blood pressure, for example. The expressive component is made up of the overt behavioural changes that accompany anxiety, such as pacing and agitation. The subjective component refers to psychological distress that can occur in the form of thinking uncontrollable thoughts and imagining terrifying scenes.

Cognitive theorists (e.g. Lazarus & Averill, 1972) suggest that anxiety occurs only once a situation has been cognitively appraised as threatening in some way. Izard does not accept this position, pointing out that cognition is itself influenced by emotional states, and that the assertion of the primacy of cognition as antecedent to anxiety does not take into account the interaction between feelings and rational appraisal.

Epstein (1972) has reviewed the various conceptions of the nature of anxiety and distinguishes three different causes. *Primary overstimulisation* leads to anxiety when the individual's limit of tolerance to a stimulus is exceeded. Epstein proposes that this limit is biologically determined and is independent of other environmental factors such as cognitive appraisal. His second class of causes of anxiety, *cognitive incongruity,* refers to the situation where the individual is not able to integrate a situation into their particular schema of the world, and his third, *response unavailability,* refers to those situations where a response to a stimulus cannot be effected - because the response is not in the individual's repertoire, for example, or the object producing the anxiety is unknown to the individual. These three categories are causes of *state* anxiety.

1.5.4.1 **State and trait anxiety**

A distinction can be made between feelings of anxiety that are transitory and the underlying predisposition to experience anxiety. Cattell & Scheier (1960) have termed these two factors *state* and *trait* anxiety respectively, although Spielberger (1966) is generally credited with popularising the terms and was responsible for developing the State Trait Anxiety Inventory for their measurement.

Spielberger's theory of Trait-State Anxiety can be summarised as follows (Spielberger, 1972). An individual will experience a state anxiety reaction ("A-state") when confronted with a situation that is appraised as threatening. This reaction will be perceived as unpleasant, be proportional to the perceived amount of threat, and persist as long as the situation is perceived as threatening. Defence mechanisms, either behavioural or psychological, will be initiated in the presence of A-state, and may develop into specific coping mechanisms which reduce A-state. Further, individuals who are high in trait anxiety (A-trait) will perceive A-state provoking situations as more threatening than those low in A-trait. This predisposition can be thought of as learned, building on prior (particularly childhood) experiences.

State anxiety is characterised by heightened psychological arousal, observable physiological reactions such as sweating or trembling, internal physiological reactions such as raised heart rate, blood pressure, breathing and gastrointestinal changes, and gross motor behaviour such as "freezing" or agitation. In short, by those universally accepted symptoms of the typical anxiety reaction.

Trait anxiety on the other hand is somewhat more problematic. Spielberger conceptualises trait anxiety as an individual's latent predisposition to perceive a wide variety of situations as threatening and to react to those threats with anxiety symptoms. Spielberger therefore regards the *person* as most important. Other theorists (e.g. Endler, 1975) propose that the *situations* which evoke anxiety responses are more useful descriptors of trait anxiety, and argue that a composite of specific state anxiety provoking situations provides a more useful indication of trait anxiety. This does not appear to be a particularly useful approach since the range of anxiety-producing situations is so large. Spielberger's conception of a *general* trait offers more generalisable hypotheses.

For the purposes of this research *state anxiety* will refer to the transitory, observable (or reported) symptoms of anxiety experienced in specific situations; *trait anxiety*, following Spielberger, will refer to a latent predisposition to experience state anxiety. Appropriate measures of state and trait anxiety will be discussed in chapter three.

1.5.4.2 **Cognitive and somatic anxiety components**

Building on the notion that anxiety is not a unitary phenomenon, several authors have argued that anxiety tends to present primarily in one of two different ways for different people (e.g. Buss, 1962; Steptoe & Kearsley, 1990), and that the primary type of anxiety presentation might properly be explored as the most effective target for therapy (Lazarus, 1973). To this end, it has become useful to distinguish between feelings of anxiety which can best be termed *cognitive*, and those which can be termed *somatic*. These two distinctions correspond broadly to Izard's subjective component on the one hand and his neurophysiological and behavioural-expressive components on the other.

Hamilton (1959) identified two components of anxiety reactions by factor analysis, which he termed *psychic* and *somatic*, and Barratt (1972) reports the results of his item analyses of questions on anxiety measuring instruments as two clusters: one representing the awareness of somatic changes and the other representing the awareness of unpleasant feelings. These two facets of anxiety symptoms can be interpreted in terms of the broader theory of "individual response stereotypy" proposed by Lacey & Lacey (1958), who demonstrated that individuals tend to respond to different stressors with consistent and stereotypic physiological arousal symptoms.

To summarise, anxiety is not a unitary phenomenon. The transient emotions and physiological reactions associated with anxiety can be termed state anxiety, while the latent predisposition to experience state anxiety in a range of situations can be termed trait anxiety. Individuals report responding to anxiety provoking situations with symptoms which can be described as primarily cognitive and those which can be described as primarily somatic.

1.5.4.3 **Anxiety and psoriasis**

Fava et al (1980) used the Anxiety subscale of the Kellner-Sheffield Symptom Rating Test (SRT) with hospitalised psoriasis patients. On the subscale that measures anxiety, the psoriasis group had a mean of 0.76, the urticaria group 0.91, and the fungal infections group 0.48. The difference between the groups was statistically significant. Similarly, in the Lyketsos *et al* (1985) study (see above) the psoriasis group scored very significantly higher than the non-psychosomatic controls on the anxiety scale of the SADS (psoriasis mean 7.1, control 0.8) - once again the sample was drawn from inpatients.

Price *et al* (1991), using the HADS, found that the patients on the whole scored moderately high on the Anxiety scale of the HADS. Price *et al* point out that 26% of the patients could be categorised as definite cases of anxiety on HADS criteria (mean psoriasis

therapy group 8.9, psoriasis controls 9.2). Examining the trend in anxiety scores over time, those authors showed that anxiety in the therapy group decreased, and at six months differed significantly from the control group. They also note that psoriasis in the therapy group appeared to clear more than the control group, but this was not statistically significant. However, the measure of disease severity was, as the authors point out, extremely crude, which may obscure any trend here.

Using the depression-anxiety subscale of the Structured and Scaled Interview to Assess Maladjustment, Baughman & Sobel (1977) categorised 15% of psoriasis patients (n=48) as having minimal anxiety, 12% as mild and 6% as moderate. They did not attempt to relate these ratings to the disease severity, but in a prospective study of stress and psoriasis, Gaston *et al* (1987) employed as one of their measures the Psychological Distress subscale of the Psychological Adjustment to Illness Scale, which measures anxiety and depression. Using a time-series design with five patients, the authors found a significant correlation between psoriasis severity (measuring the scalp only) and psychological distress.

To summarise, most researchers have reported that both in- and outpatient psoriasis sufferers have raised anxiety levels. Two studies have shown that anxiety is related to change in the severity of psoriasis, but in one of those the method of measuring severity was crude, and in the other only the scalp was assessed.

1.6 **Conclusions and hypotheses.**

Both Hughes *et al* (1983) and Wessely & Lewis (1989) found high prevalence of psychiatric "cases" in dermatology outpatients, but neither of those authors examined rates specific to psoriasis. The first hypothesis to be examined in the study reported in Chapter 3 is therefore that more psoriasis outpatients will present as "cases" than controls.

Patients reports about their psoriasis indicate that they feel very embarrassed about visible lesions and that they feel this effects their social and work experiences. Studies which have examined depression in psoriasis patients have for the most part concentrated on those hospitalised for their condition and have consequently found levels above those in the general population, but have also found that psoriasis in-patients tend to be more depressed than general medical in-patients. Those few studies which have used psoriasis outpatients have provided inconclusive evidence about whether they are more depressed than controls. Those that have found raised levels have found that they have not reached standard criteria for clinical depression. Psoriasis in-patients appear to have unusually high levels of depression, yet only two studies have attempted to link depres-

sion levels to disease severity (Gupta *et al*, 1991; Price *et al*, 1991). Gupta used in-patients as his subject group, all of whom had severe psoriasis, and it has not yet been demonstrated in an out-patient sample whether this link still holds for less severe psoriasis. This is the second general aim of the research reported in the following chapters.

Closely linked to levels of depression are levels of self-esteem. Psoriasis sufferers report severe embarrassment over their condition, as well as feelings of shame and guilt. The results of Ginsburg & Link (1989) suggested that psoriasis sufferers may have low self-esteem, which varies with the length of time they have had the condition. However, while Ginsburg's results were suggestive of low self-esteem, their work was primarily concerned with feelings of stigmatisation, and no other research has addressed specifically the question of whether or not self-esteem is affected in psoriasis. This, then, is the third general aim of the current study. There is limited evidence that psoriasis outpatients are more anxious than controls, and the studies which have attempted to ascertain whether anxiety varies with the severity of the condition do not use adequate means of assessing severity. Confirmation of the relationship between disease severity and anxiety is the fourth general aim of this research.

In summary, levels of depression, anxiety and self-esteem are to be assessed, together with the severity of the condition. It is hypothesised that more severe psoriasis will be associated with higher levels of depression and anxiety, and lower levels of self esteem.

Chapter Two

The Assessment of Psoriasis Severity

2.1 **Introduction**

To examine any relationship between psychological variables and the severity of psoriasis a reliable and valid means of *assessing* severity must be used. The first part of this chapter reviews the existing means of assessing psoriasis severity. The second part of this chapter describes the development of a computer program to give an objective means of recording and assessing psoriasis severity, and reports on its validity and reliability.

2.2 **Psoriasis severity**

The "severity" of psoriasis is a nebulous concept whose definition is dependent upon the purpose of the investigation. The dermatologist may be interested in primary clinical signs such as thickening, scaling and erythema and how these change as the disease progresses. Researchers whose interests lie in the genetic control of lesion positioning information (e.g. Goudie, Spence & Sconthorne, 1980) may be less interested in clinical signs but more interested in the *distribution* of psoriasis lesions over the body, while psychologists interested in the effect of psoriasis on psychological variables may require a measure of psoriasis severity that focuses primarily on the area of coverage, or on the area of coverage on visible body regions. The patient, on the other hand, may regard pain and discomfort, or feelings of embarrassment associated with the appearance of the condition as the most important indicators of severity (e.g. Baughman & Sobel, 1970).

These different standpoints lead in practice to different assessment strategies and the use of a range of technical aids. In a study of the assessment strategies used by dermatologists, Marks and his colleagues (1989) undertook a survey of all published papers which reported a clinical assessment of psoriasis in the *British Journal of Dermatology*, *Clinical and Experimental Dermatology*, *Archives of Dermatology*, and the *Journal of the American Academy of Dermatology* for the years 1985 and 1986. In the thirty papers they reviewed, they confirmed that a wide variety of techniques were being used, measuring a range of different features. These fall broadly into two categories: assessment of clinical signs, and assessment of area of coverage.

2.2.1 **Assessment of clinical signs**

Mechanical and electronic aids are available for assessing clinical signs, but they can be expensive and unwieldy to use, and have not always been shown to provide valid and reliable results.

Reddening (erythema) can be assessed by matching skin colour to standard colour patches, but as yet no standard colour grading has been defined, making comparisons between studies difficult. Another method which has been refined recently for dermatological use is reflectance spectrophotometry. Diffey, Oliver and Farr (1984) have designed a relatively compact instrument capable of measuring reddening, which produces an "erythema index" with a reported coefficient of variation of 3% when used repeatedly on a single site. While the accuracy of this instrument is impressive, it is not yet commercially available, requires specialist training to operate, and although its size is more acceptable than previous instruments (e.g. that described by Wan, Parrish & Jaenicke, 1983), it is still too cumbersome for use outside the hospital environment.

Scaling (desquamation) has been measured in a variety of ways, none of which are entirely satisfactory. One method is to cover a lesion with sticky tape then pull the tape off. The scales stripped away can then be assessed: either visually or by weight. Clearly this is quite unpleasant for the patient and the resulting figures are difficult to evaluate. A more accurate method has been developed by Marshall & Marks (1983) using densitometric assessments of macro photographs of skin lesions. While they have shown that scaling can be assessed by this method, it does suffer from the drawbacks of requiring specialist equipment, trained operators, and standardised lighting conditions, and the results are not available until the photographs have been processed and densitometrically analysed.

Thickening of the skin can be measured accurately by high resolution ultrasound (e.g. Tan, Marks & Payne, 1981) or by "pinch" callipers (e.g. Dykes, Frances & Marks, 1976). Ultrasound equipment is very expensive and cumbersome, but measurement with callipers is relatively easy and quick for large lesions. However, callipers are difficult to use on small lesions because the skin needs to be folded at 180°; psoriasis lesions are often small, making this technique unsuitable.

Because of the drawbacks of these techniques, most clinicians have tended to rely on visual ratings of clinical signs on three-, five- or seven-point scales. If the purpose of estimation is to evaluate subtle changes in the skin brought about by the application of different treatments, this approach may not be appropriate. However, for a general measure of disease severity, rating erythema, scaling and thickness as mild, moderate or severe (for example) does provide adequate assessment.

While not a primary clinical feature of psoriasis, itch (pruritus) is sometimes assessed as part of a measure of severity, and mechanical instruments are available for the indirect

measurement of itch through the measurement of scratching. Summerfield and Welch (1980) have used a wrist-watch type meter for measuring scratch, and Felix & Shuster (1975) developed a bed that purported to measure scratching by measuring limb movement. Part of the problem with these measuring techniques is that limb movements may not in reality correlate with scratching nor, in turn, with itch. Generally, those researchers who have assessed pruritus in psoriasis patients have relied on self-report measures.

Ten papers attempted to assess reddening by visual estimation on scales ranging from three points to seven points. Scaling and thickening were assessed on three- to nine-point scales in eleven papers. The authors note that only two articles made any attempt to operationalise reddening or scaling. Itch was assessed on similar scales in four studies.

To summarise, the clinical signs of erythema, scaling and thickening can be assessed accurately in principle, but Marks' review of the literature has shown that in practice, if they are assessed at all, a simple rating scale is used. It may be possible to relate scratch to the symptom of pruritus, but this may not give reliable results. Pruritus is most often assessed by patient self-report.

2.2.2 **Area of coverage**

In Marks' review, while all included some form of assessment of area of coverage, only nine out of the thirty studies assessed the total percentage of the body covered by psoriasis: the remainder assessed coverage at between one and seven sites. In general, techniques for the assessment of the area of psoriasis lesions fall into three categories: patients' descriptions, physical measurement, and visual estimation.

Patients' verbal descriptions provide an estimate of psoriasis coverage which may be used when the specific extent of psoriasis is not required but the distinction "present" or "not present" is important, but they are inherently inaccurate. Patients may not be able to see their psoriasis, and indeed may not be aware that they have any psoriasis at all on hidden parts of the body, particularly if they are not treating the psoriasis themselves.

Methods are available for the physical measurement of skin lesions. An indirect measure of area of coverage that has been used involves the researcher tracing lesions onto clear film then measuring the traced areas. While this does provide quite accurate information, it is very time consuming and unpleasant for the patient. A similar technique is to draw the psoriasis on standard templates, then to measure the area from these

templates (e.g. Farber & Nall 1968, 1974). This is most often used in hospital settings to keep records of disease progress. Instruments which measure directly the dimensions of skin lesions are available (e.g. callipers or stylus tracking), but are time-consuming in use and unpleasant for the patient. One accurate method of measuring the area of coverage of skin lesions is planimetry: computerised digital image analysis. Photographs of affected body parts are projected onto an image analyser digitising tablet and the resulting data gives information on the area covered by psoriasis (e.g. Marks *et al*, 1989). The major problem with planimetry for dermatological assessment is that subjects must be photographed under standardised lighting conditions, which is seldom practical outside the hospital environment.

To summarise, area of coverage can be measured by a variety of means, but available methods are either inherently inaccurate or impractical outside the hospital environment.

The most widely used method of estimating the area of coverage of psoriasis is visual assessment by the clinician. Most often this takes the form of simply looking at the affected area and estimating a percentage coverage. However, two variations on this approach are sometimes used. Wallace (1951) suggested a strategy using the "Rules of Nine" procedure, whereby visual estimates of coverage are made on different body regions, which in turn are taken to represent fixed percentages of the total body area. The head and each arm are each taken to represent 9% of the total body area respectively, while the torso front and back, and each leg represent respectively 18%. The genital area represents 1%. Estimates for each area are combined to give a total body coverage figure. Another estimation strategy uses the premise that the hand approximates 1% of the body area. Coverage estimates are made by assessing lesion size against hand size (e.g. Stern *et al*, 1986). Marks' study has demonstrated that these estimation strategies are seldom, if ever, used in practice, and they still require the rater to assign numerical values to lesion areas. This is the heart of the problem of area estimation in psoriasis.

2.3 **General evidence for problems with visual area estimation**

Regardless of the *strategy* used, there are certain problems inherent in area estimation which suggest that visual ratings are likely to be inaccurate. Psoriasis lesions are most often discoid or of polycyclic outline due to expansion of several lesions to form one large plaque, and the evidence reviewed below suggests that raters are not able to estimate accurately the true area of disks. This is supported by further evidence, also reviewed below, that in a clinical situation, estimation of the area of coverage of psoriasis, even by trained dermatologists, does not provide reliable results.

2.3.1 Psychological evidence for problems with visual area estimation

A great deal of research has been undertaken in the field of cartography on the perception of the area of disks used as map symbols, a problem directly analogous to estimating the area of psoriasis lesions on the body. Much of the work can be traced back to Stevens (1957), and to Fechner before him (1877, quoted in Stevens, 1957), and starts from the observation that perceived area (in general, but also disk area in particular) is proportional to true area raised to some power. In Stevens' terms:

$$\Psi = kS^n$$

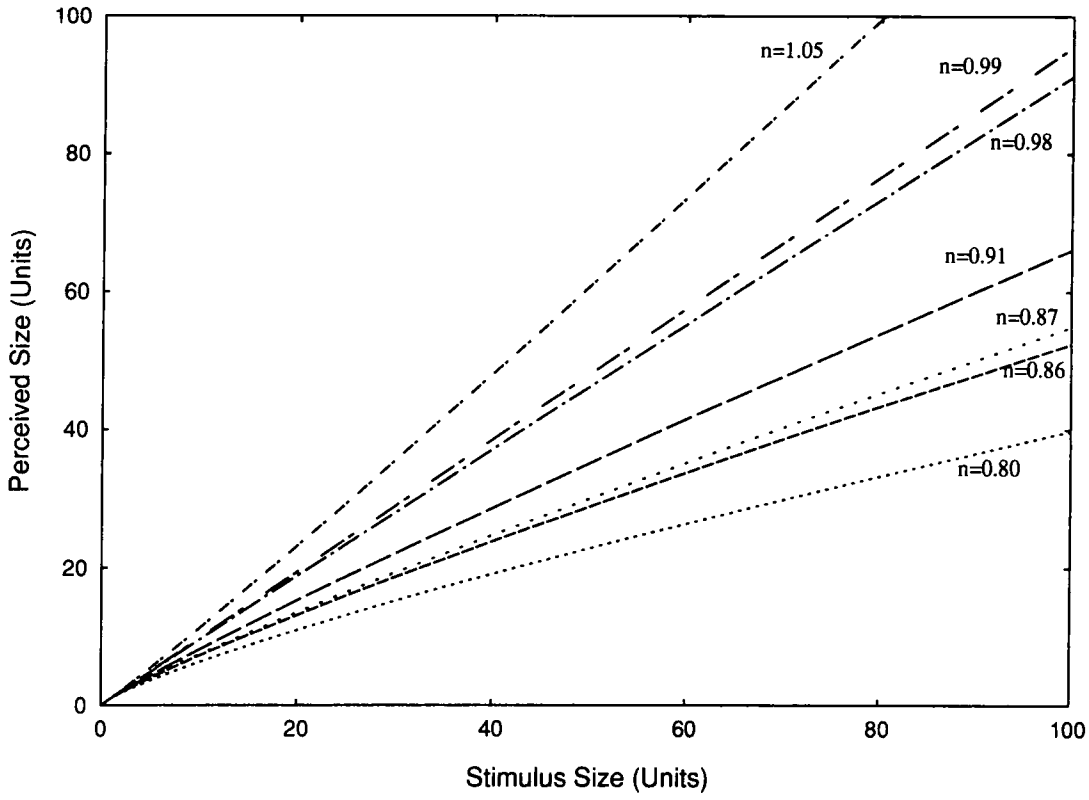
where Ψ is the perceived area, S is the true area, k is some constant appropriate to the scale of measurement, and n is the power coefficient. This leads in practical terms to the assumption that true area can be calculated from estimated area if only the appropriate power coefficient is known. It is from here that the cartographic literature proceeds, with several studies attempting to discover a power coefficient associated with judgments of disk area. Several studies have reported empirically derived power coefficients for disk area estimation and these are reported in Table 2.1.

Table 2.1 Power coefficients derived by empirical studies into the relationship between perceived and true stimulus size using circles or disks.

Source	*Power Coefficient*
Ekman, Lindman & William-Olsson (1961)	0.80
Ekman, Bergstrom & Kuennapas (1956)	0.86
Flannery (1971)	0.87
Crawford (1971)	0.91
Ekman & Junge (1961)	0.98
Ekman & Junge (1961)	0.99
Ekman & Junge (1961)	1.05

MacDonald-Ross (1977) in an extensive review of techniques for the visual presentation of data suggested that these coefficients represent "quite good agreement, considering all the problems that beset the researcher" (p.373). However, when they are translated into predicted estimates of true area over an appropriate range, the difference between the functions is quite pronounced (Figure 2.1), and even the mid-range coefficients do not give comparable results at larger true areas. Therefore, in the absence a reliable, universal power coefficient linking perceived area to true area, it is not possible simply to apply a correction calculation to estimates of disk area in general.

Figure 2.1 Plots of the relationship between perceived size and stimulus size at a range of empirically derived power functions (n).



There is further evidence from cartography to suggest that perception of disk area may be problematic. Meihoefer (1969) presented untrained subjects with a range of circles of differing sizes distributed at random on a white page, and asked them to estimate the area of each circle relative to a standard circle. His results suggested that while subjects indicated that they thought their estimates were precise, in fact they were quite poor at estimating areas, particularly if the circles were relatively similar in size. Further, larger area variations were required for subjects to perceive differences between larger circles than smaller ones. Perhaps more importantly, the estimate errors were distributed over a wide range and did not follow any pattern of under- or over-estimation. Meihoefer does not offer any measure of the distribution of his data, but his plots of responses to the six test areas do indeed show wide variation.

These results were subsequently replicated by Meihoefer (1973) for filled circles (disks), but in an important extension of his work he showed that even though subjects were not able to estimate *absolute* area accurately, they *were* able to match one disk size to another. That is, when subjects were required to choose matching circles, they accurately chose circles that matched standard legends. Meihoefer evaluated performance on this task by plotting errors of estimation, and his plots confirm that almost all

the estimation errors were close to zero. Unfortunately, Meihoefer does not report his raw data and does not analyse these errors statistically other than reporting a mean and mode error of zero, but notes that "these results are so strikingly conclusive that statistical analysis of these tests would be redundant" (p.78), and that 95% of his sample perceived matched circle sizes correctly.

One question that arises from this research is whether a more precise correction coefficient can be obtained if subjects are trained in estimating area and given suitable feedback about their errors. This was examined by Olson (1975), who compared subjects estimates of relative circle areas before and after training on labelled pairs of circles. His results were interesting and inconclusive. While the power coefficient before training was 0.71, after training it rose to 0.97, which represents a clear improvement and a final coefficient quite close to unity. However, while the power coefficient (which was based on the median ratings) did improve, the distribution of estimates (reflected in the interquartile ranges) appeared to *worsen* after practice, and for half the circles the range of estimates increased after practice. Olson concluded that practice does not, therefore improve the precision of estimated area of coverage.

To summarise, psychological theory (e.g. Stevens, 1957) predicts that perceived circle or disk area will be related to true area by a power function, but empirical evidence has failed to ascertain a reliable power coefficient to allow corrections to area estimations to be made in circle and disk studies. While the median estimate of area better approximates the true area after practice, the spread of estimates actually increases after practice.

There is reason to suggest, therefore, that estimates of area of coverage of psoriasis (which presents as disks on the body) are unlikely to be either consistent or accurate.

2.3.2 **Direct evidence for problems with visual area estimation in psoriasis studies**

In order to ascertain whether trained clinicians were able to assess area of coverage in psoriasis accurately and consistently, Marks *et al* (1989) investigated area estimation in a more practical setting. They chose to examine the relationship between assessed area of coverage and true area of coverage on colour transparencies of psoriasis patients. By adopting this strategy they were able to obtain a planimetric assessment of the actual area that was covered on the transparency and compare that with clinicians' estimates of the area of psoriasis on the transparency. They compared the assessments by four experienced clinicians of the area of coverage of psoriasis on ten patients, both against the

planimetric values and against each other. The results for the assessed percentage of the area involved and the planimetric assessments are summarised in Table A2.1 (Appendix 1). Marks *et al* do not report planimetry and estimates for individual transparencies; rather they report figures for body regions, which are composites of several transparencies ("Legs", for example is a composite of two transparencies - front and back).

Marks *et al* chose to analyse their data using Friedman two-way analysis of variance in order to avoid assumptions of homogeneity of variance and normality of scores. Their analysis showed the rank ordering of area of coverage by each clinician to be significantly different ($p<0.001$). They also tested whether clinicians varied in the amounts by which their estimates differed from the true (planimetric) values, i.e. in *difference* scores. Again, they used a non-parametric statistic (Kruskal-Wallis) and found a significant difference between raters. However, parametric statistics supply more useful statistical information, since it is the *size* of errors that is more important than the ranking of estimates.

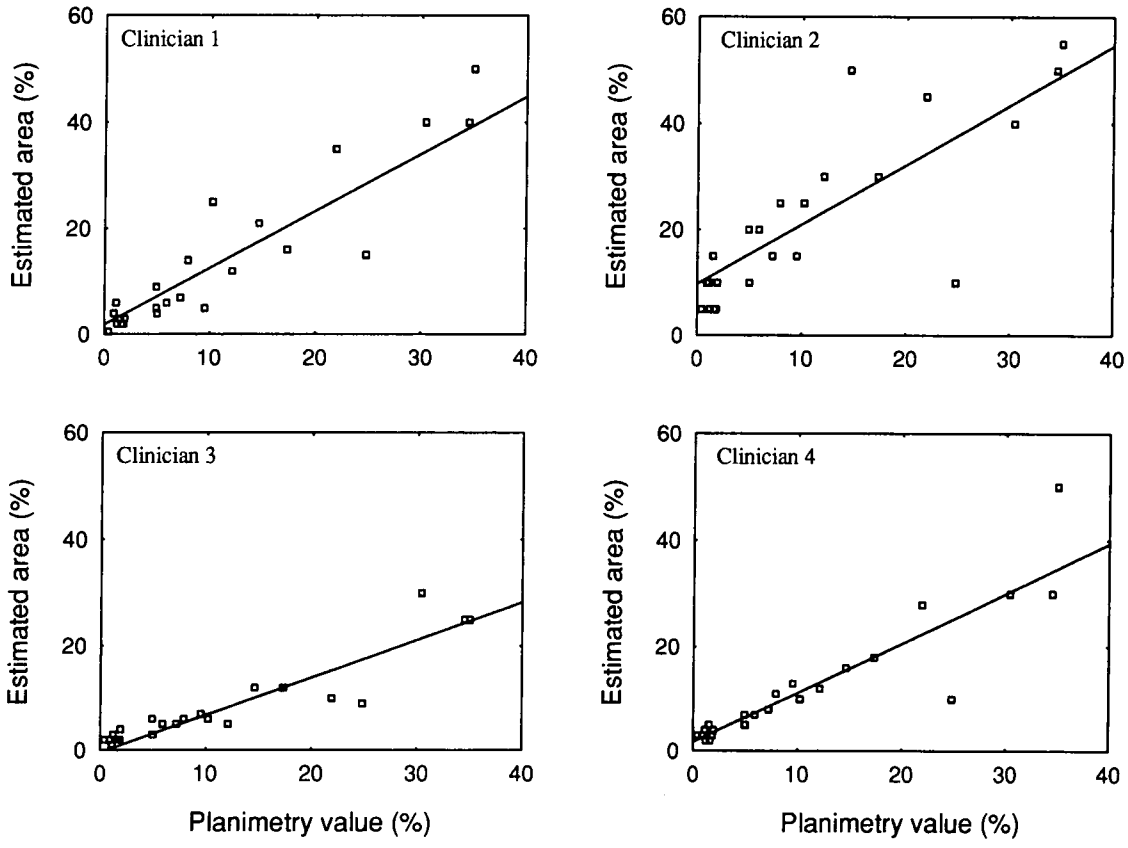
The data were reanalysed by the author using GLIM 3.77 to produce regression models for each clinician: the results are presented in Table 2.2. The estimated area and planimetric values are plotted in Figure 2.2, together with the regression lines for each clinician.

Table 2.2 Coefficients and residual errors from regressing estimated area on planimetric area for 4 clinicians assessing 25 body regions. The t-test for the intercept tests for a significant difference from zero; the t-test for the slope tests for a significant difference from 1 .

Clinician	*Intercept*	*S.E.*	*t*	*sig*	*Slope*	*S.E.*	*t*	*sig*	*Residual SS*
1	1.87	1.50	1.25	-	1.074	0.074	1.00	-	755.8
2	9.79	2.37	4.13	<0.001	1.12	0.12	1.03	-	1897.4
3	–0.42	0.93	–0.45	-	0.79	0.046	–4.60	<0.001	291.1
4	1.78	1.26	1.41	-	0.94	0.062	–0.96	-	540.0

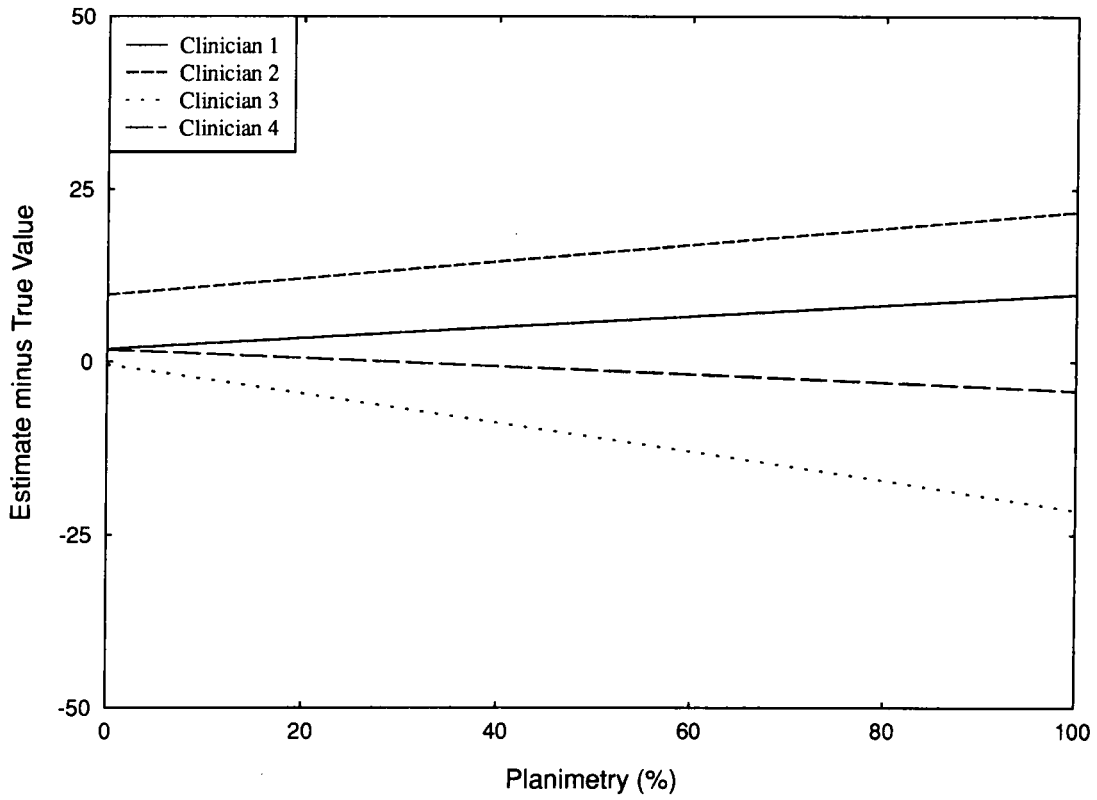
The question is how each clinician performs in estimating area of coverage. This can be divided into two issues: how accurate are the mean estimates from each clinician, and how large are the errors around the mean?

Figure 2.2 Regression of estimated area of coverage on planimetric values for four clinicians (original data from Marks *et al*, 1989).



Mean accuracy was determined by regressing the estimated area on the planimetric area for each clinician. The regression line is unbiased even though the data are not normally distributed with constant variance. From the regression coefficients for each rater given in Table 2.2 it can be seen that the intercept for clinician 2 is significantly greater than zero. All slopes are clearly significantly different from zero, but the slope for clinician 3 is also significantly different from unity. The other slope coefficients are not significantly different from unity. Thus, of the four clinicians tested in Marks' study, one tended to overestimate by about 10%, one tended to underestimate larger areas, and the other two estimated area quite accurately. The mean intercept for all clinicians is 3.25 (SD 4.48), the mean slope is 0.98 (0.15). The regression lines for the four clinicians are plotted together in Figure 2.3 as deviation from planimetry against planimetric value.

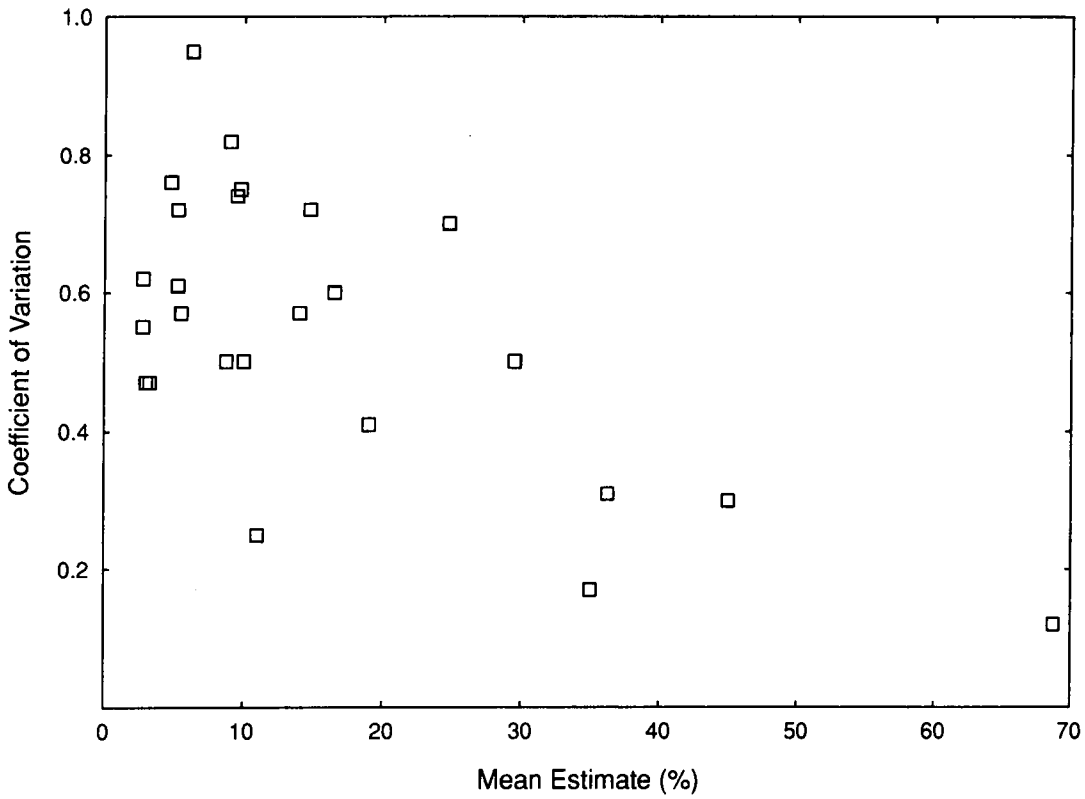
Figure 2.3 Regression of difference between estimate and planimetry on planimetric value for each of four clinicians (original data from Marks *et al*, 1989).



A measure of the variability of each clinician's estimations is the residual sum of squares (*RSS*) around the regression lines. These are presented in Table 2.2 and it can be seen that there are considerable differences between clinicians. Taking the extremes, the *RSS* for clinician 2 is 6.5 times greater than the *RSS* for clinician 3. Without *RSS* values from other studies, it is not possible to ascertain whether these values represent good or poor responses. However, given the wide range, it can be seen that individual clinicians do vary considerably in the precision of their estimates.

Inspection of the plots in Figure 2.2 suggests that the variance of estimates is not equal at all planimetric levels. Appropriate transformations require that the variance be proportional to the mean, and examination of coefficients of variation should reveal no systematic trends if this is the case. The coefficients of variation are plotted against mean estimate in Figure 2.4, and it can be seen that this is not the case with Marks' data. Thus, since the variance of estimates is neither constant nor proportional to the mean estimate, no simple transformation is appropriate for these data.

Figure 2.4 Coefficients of variation for each body region plotted against mean estimate of area of coverage (original data from Marks *et al*, 1989).



To summarise, from Marks' data it cannot be concluded that clinicians are able to estimate area of coverage of psoriasis accurately - only two out of four clinicians were able to produce estimates that did not differ systematically from the true values. Further, there is no consistent pattern to the spread of estimation errors, suggesting that raters are not precise in their estimates. So, psychological and cartographic evidence suggests strongly that the perception of disk area is not accurate when subjects are required to assign values, but that individuals *can* reliably match one patch to another. Direct evidence shows that dermatologists do not rate area of coverage of psoriasis either accurately or consistently. Thus, before area of coverage in psoriasis can be used as an independent variable, a more valid and reliable means of *assessing* area of coverage must be found.

2.4 Computer aided visual assessment

Based on the evidence (above) that stimulus disks can be matched accurately to template disks, it was decided to write a computer program which would allow representation of psoriasis lesions on a VDU showing pictures of body regions. The program, rather than the rater, could then calculate the area of coverage of those patches, thus avoiding the estimation stage of area of coverage assessment. A computer was chosen for this task for several reasons. First, while accurate methods of assessing area of coverage are available - e.g. planimetry (see above) - they require specialist equipment which is not generally available. Marks (1985) and Marks *et al* (1989) have urged researchers to use the same or comparable measures of psoriasis severity (of which area of coverage is a major component) so as to facilitate comparison of results between studies. In keeping with the spirit of this request, planimetry was rejected as a general means of assessing area of coverage in favour of a computer-based method. This also guided decisions about the type of computer the program would support. At the time the program was written, the most popular PC configuration comprised an 8086 (or at best 80286) processor, CGA graphics adaptor and 5 1/4 inch floppy disk drives. The program was therefore written to best use this configuration.

The second reason for choosing a computer for assessing mapped areas was that its use requires no specialist skills, other than basic familiarity with PC operation. Thus, minimal instruction or training are necessary for any researcher or clinician to use the program in their work. The third reason relates to more pragmatic concerns about data collection in general. Collecting information directly onto a computer removes two stages from the data collection and analysis process: data coding and data entry. Both of these stages, apart from being time consuming, increase the possibility of introducing errors. Their avoidance removes this possibility.

The development and validation of the computer program - to be called SKINMAP - is described below.

2.4.1 Outline of the SKINMAP computer program

The purpose of SKINMAP is to facilitate accurate assessment of the area of coverage of skin lesions in general, and those in psoriasis in particular. The program was designed so that the computer draws body shapes on the screen then allows the user to position representations of psoriasis (or any other skin lesion) in appropriate places on the screen. The computer then calculates the area of coverage based on pixel areas and stores this to disk. Since clinical signs can be an important part of assessing disease severity in psoriasis, SKINMAP was designed also to allow recording of assessments

made by either visual rating or by electronic measurement, of other disease-characteristic features such as reddening, thickening and scaling. Provision was made for SKINMAP to combine these diverse assessments into a single "severity" figure (for example, the PASI score proposed by Fredriksson and Pettersson, 1978), with the exact calculations specifiable by the user. This program was conceived such that it could be used in a variety of clinical and research settings, so a further section of the program was developed to facilitate clinical comparisons of disease progress which allows visual presentations of previous assessments simultaneously on the screen.

In short, while the immediate purpose of SKINMAP was to assess area of coverage in psoriasis sufferers, it was designed to be a general purpose assessment tool for dermatological use.

2.4.2 **SKINMAP program development**

Since the research presented in this thesis was to involve assessing psoriasis patients in their own homes, it was essential that SKINMAP be able to run on a portable "lap-top" computer. This immediately imposed certain restrictions on the design of the program. First, the update time on available LCD-based screens at the time the program was written was relatively slow, so screen modifications needed to be kept to a minimum. Second, disk storage was limited, so saving screens as "bit-mapped" images was not feasible, and third, disk access was slow and consumed a relatively large amount of power, so for efficient operation and reasonably long battery life, disk access needed to be kept to a minimum. These were the guiding factors in program development.

SKINMAP was written in Turbo Prolog® and Assembly Language (for reasons of copyright protection a program listing is not appended). Turbo Prolog was chosen as the main programming language for two reasons. First, it has well developed and powerful external database functions which facilitate rapid and safe storage and retrieval of data. Second, it has advanced graphics capabilities built into the language as standard predicates. It does have the disadvantage of producing executable code with a high program overhead, so executable programs tend to be very large in Turbo Prolog, but this was acceptable in the light of the considerable advantages it offers. In the first developmental version of SKINMAP, all operations were executed through Turbo Prolog predicates. After testing however, it became clear that some operations were simply too slow, so in the second version (used throughout this thesis) those functions were replace with Assembly Language routines - counting a screen full of pixels, for example. The graphics mode selected by SKINMAP is 640 × 200 pixels in either CGA or EGA/VGA mode, depending on which adaptor it detects. There is no significant visible difference between the adaptors at this resolution.

2.4.3 **Representation of body regions**

A variety of body representations were tried in order to find the most useful way of displaying different regions. The first set used in version 1 of SKINMAP comprised highly stylised line drawings using a minimum of straight lines to outline a filled polygon - which formed the body shape. Contours were added to the body regions with straight lines. While this approach did facilitate very rapid drawing of the regions onto the LCD screen, they tended to look too artificial and "mechanical". Consequently in version 2, line drawings from biological textbooks were converted into filled polygons, again with contours represented by straight lines. The areas represented were arms (front and back), hands (front and back), legs and feet (front and back), torso (front and back) and face. Androgynous shapes were chosen to avoid the necessity of duplicating body regions for males and females. An example of a typical body region (with psoriasis patches drawn) is shown in Figure 2.5.

2.4.4 **Representation of psoriasis lesions**

Psoriasis lesions are represented by filled ellipses which can be varied in size and moved over the body region by use of a mouse or the cursor keys. Large psoriasis patches tend to be polycyclic, and these can be built up from smaller ellipses.

2.4.5 **Method of operation**

Before any mapping can be performed, the patient's identifier (which may be their name, but for the sake of confidentiality may be some other alphanumeric identifier), date of birth, and sex must be entered. Within the database, each patient is uniquely identified by a composite of their identifier, date of birth and sex. If a previous record for the patient exists, the new record is appended to the database chain associated with that patient, if not, a new database chain is created. The first screen of SKINMAP allows the user to chose between *a)* drawing, *b)* viewing a patient's previous records, or *c)* outputting the data in a specified format.

a) Drawing

Body regions are presented sequentially on the screen. All body regions are presented for all patients to avoid the possibility of missing any. Psoriasis lesions are then mapped by the user onto the region: their size can be changed, and they can be erased if necessary. Once the psoriasis has been mapped, the user signals the program to calculate the area of coverage, which is stored together with the coordinates and size of each ellipse. The next screen contains the identical body region onto which the mapped lesions have been redrawn, and here there is the option of superimposing blank patches to remove certain areas from the area calculations. In this way, a coverage figure can be obtained

for individual areas of the body (lower arms only, for example) which may be used to evaluate area of coverage on *visible* regions, for example. Finally, SKINMAP checks whether a user-defined program exists and executes it (to prompt for ratings of any clinical features, for example, or to interface with external measuring equipment). The data collected are stored with the area assessments. This process is repeated for each of the body regions. An example of a mapped region is shown in Figure 2.5, together with an example of a blanked equivalent in Figure 2.6.

Once all regions have been assessed, SKINMAP runs another subsidiary program (if it exists) designed to allow the user to create extensions to the data collected, such as general comments, or to interface with other measuring instruments. Finally, the external database is updated and the opening menu represented. The patch locations and sizes, and all other data are stored in a temporary file at the end of each regional assessment. Should the program be terminated abnormally (through power failure, for example), SKINMAP rebuilds the representation at the start of the next session and gives the opportunity to save permanently or abandon the assessment.

b) Viewing Previous Records

The history option from the main menu presents paired mappings of body regions, together with a summary of the area of coverage of that region and the number of patches. It is possible to step through all previous assessments to view changes in the disease coverage over time. A sample of the history screen is shown in Figure 2.7.

c) Output of Data

This option writes the database to an ASCII file in user-defined format. Thus, any or all of the recorded areas and patch locations, as well as the extra data obtained from the subsidiary programs can be output in a format suitable for input to a statistics package.

Figure 2.5 SKINMAP main drawing screen. The example shows a body region with a range of patches mapped.

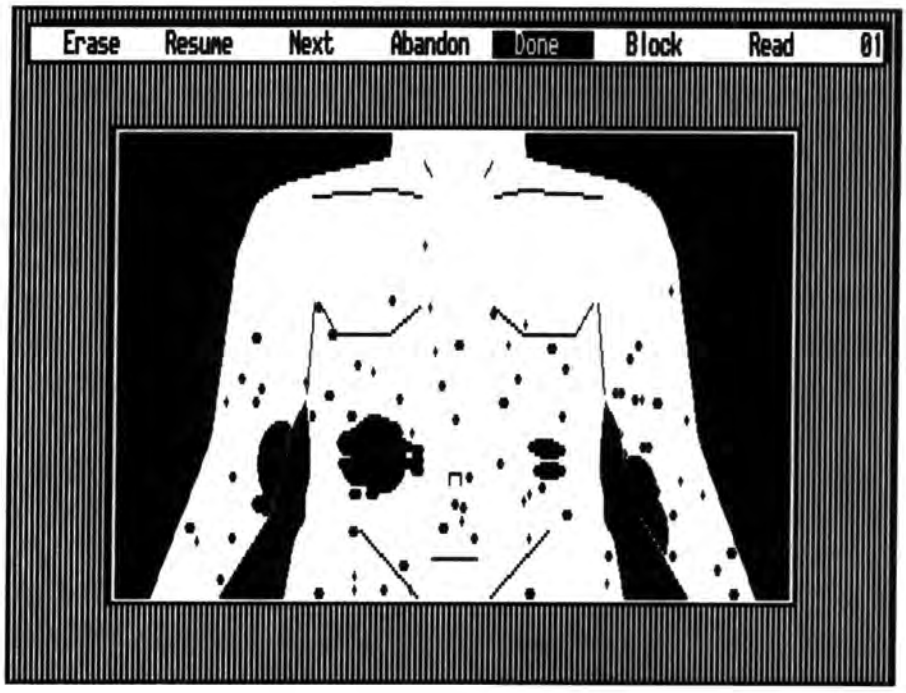


Figure 2.6 Example of the same SKINMAP body region with selected areas blanked.

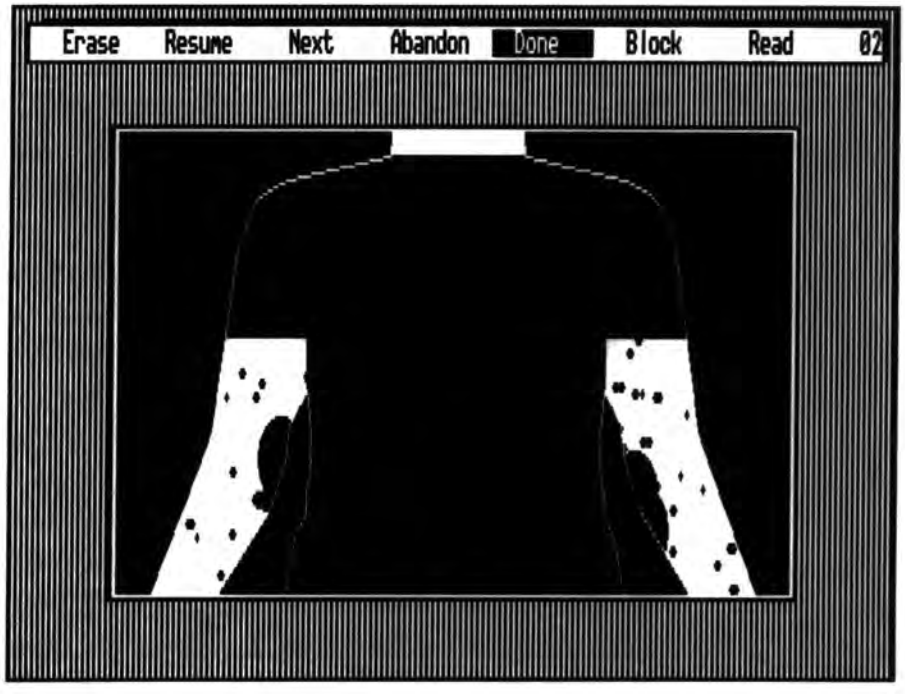
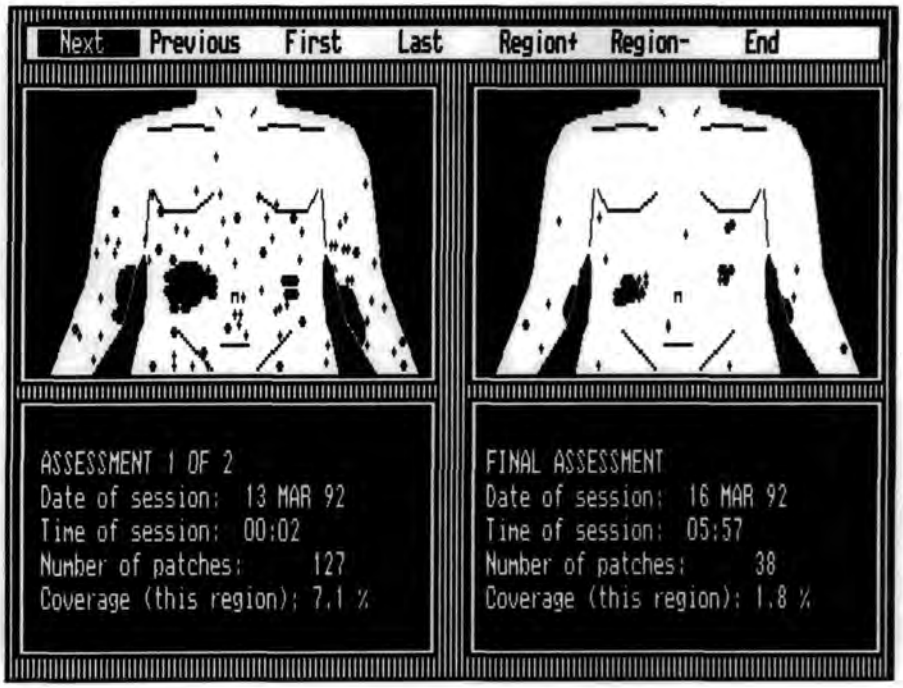


Figure 2.7 SKINMAP history option screen. The example shows assessments made on the same subject on two occasions.



2.5 Validation of SKINMAP

Before SKINMAP could be used in practice, it was important to be sure that it did indeed produce estimates of the area of coverage of psoriasis that were better than simple visual estimation. A validity study was therefore undertaken to assess how estimates made by SKINMAP compare with estimates made by visual assessment.

2.5.1 Introduction

Two groups of eight subjects were required to estimate the area of coverage of psoriasis on a series of eighteen colour transparencies. The first group used SKINMAP, the second made a visual estimation.

2.5.2 Subjects

Sixteen subjects were recruited for this study from a range of occupational and educational backgrounds. There were nine females and seven males, the mean age was 29 years (SD 16). None had any formal experience in estimating areas and none had any specific computing experience, although all had used computers before. None of the subjects were medically trained. All the subjects had seen psoriasis before, but none had ever suffered from it nor had any close relation who suffered from it. None reported any visual impairments not corrected by spectacles.

2.5.3 Transparencies

A set of eighteen colour transparencies was used drawn from the full set of 66 used by Marks *et al* (1989). It was necessary to use a subset of those transparencies because planimetric data was not readily available for the full 66. The planimetrically assessed areas of coverage ranged from 0.25% to 47.63% (Table 2.3).

Table 2.3 Planimetric assessment of the area of coverage of psoriasis on a set of 18 colour transparencies drawn from a full set of 66 used by Marks *et al* (1989).

Slide	*Coverage (%)*	*Slide*	*Coverage (%)*
10	0.25	17	21.68
5	0.31	11	22.56
2	0.62	4	25.08
9	2.18	15	27.84
3	2.38	14	30.38
18	7.59	7	33.37
1	8.78	8	35.77
6	13.52	13	39.38
16	14.06	12	47.63

2.5.4 **Equipment**

For the purpose of this study SKINMAP was run on an Amstrad 1512 computer with twin 5 1/4 inch floppy disk drives, and monochrome monitor with CGA graphics adapter. This represents a minimum standard of computer hardware necessary for SKINMAP. A mouse was used for all drawing operations. Transparencies were projected using a Kodak Carousel projector and back-projection screen.

2.5.5 **Procedure.**

Subjects were recruited in pairs then one of each pair was randomly allocated to a group by drawing numbers out of a hat, the other member of the pair was assigned to the other group giving eight subjects per group. Both groups were shown four transparencies to familiarise themselves with the condition to be assessed. These transparencies were chosen to be typical of the nature and range of psoriasis in the experimental transparencies.

None of the subjects in the computer assessment group had any experience with SKINMAP. At the start of the session the program was explained to them, and they were taken through each stage of its operation. Each of the subjects was allowed as much time as they required to familiarise themselves with the program's operation. Subjects were told they would be shown a series of eighteen transparencies and asked either to map the psoriasis as accurately as they could onto the computer screen, or to estimate the percentage of the body region that was covered by psoriasis, depending upon to which group they were assigned. Results were recorded either directly by SKINMAP in the computer aided assessment group (SKINMAP group) or by hand in the visual estimation group (visual group). The time taken to assess each transparency was also recorded.

All subjects were tested in the same room. Use of the the computer requires some ambient light so artificial room lighting was kept on and daylight excluded. The 35mm colour transparencies were back-projected to give a maximum image height of 24 inches and were viewed from approximately 48 inches, although subjects were advised to adopt the most comfortable viewing distance. Slides were presented in random order.

2.5.6 **Results**

All subjects in both groups completed all the assessments, giving a full set of data for each of the 18 transparencies. The mean ratings (± SD) for each transparency for visual estimation are presented in Figure 2.8 and for SKINMAP estimation in Figure 2.9.

Figure 2.8 Visual estimates of area of coverage on 18 transparencies. Plot shows mean ± SD

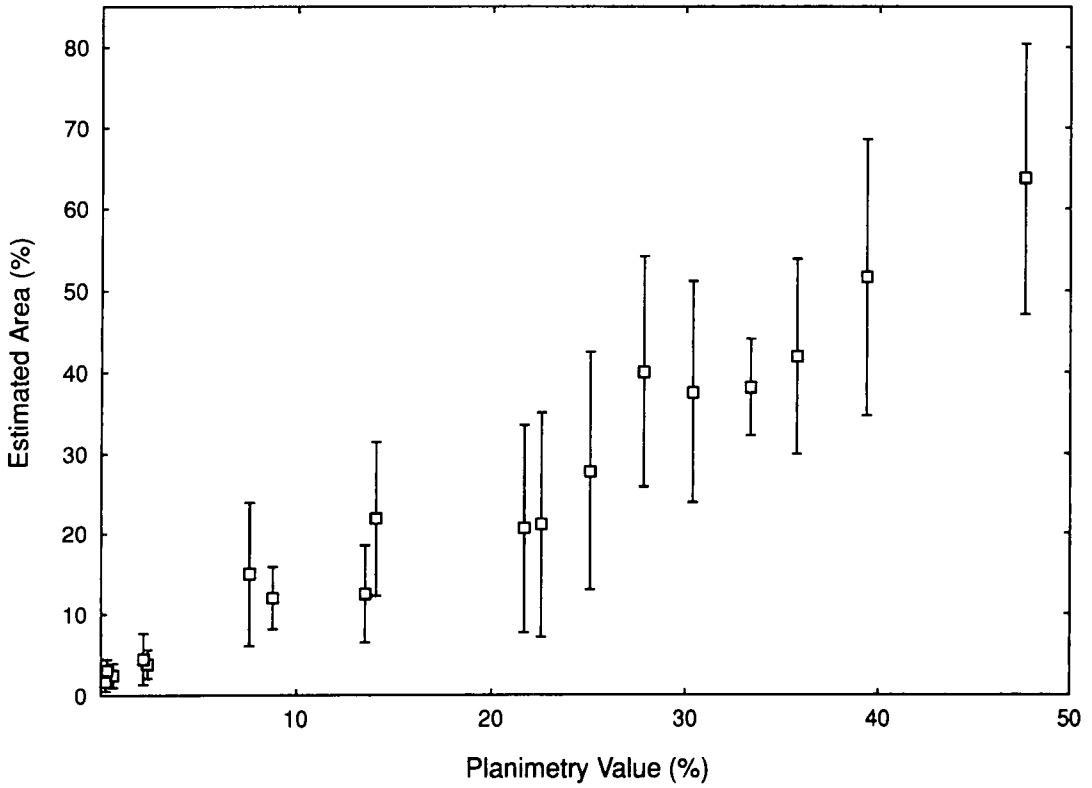


Figure 2.9 SKINMAP estimates of area of coverage on 18 transparencies. Plot shows mean ± SD

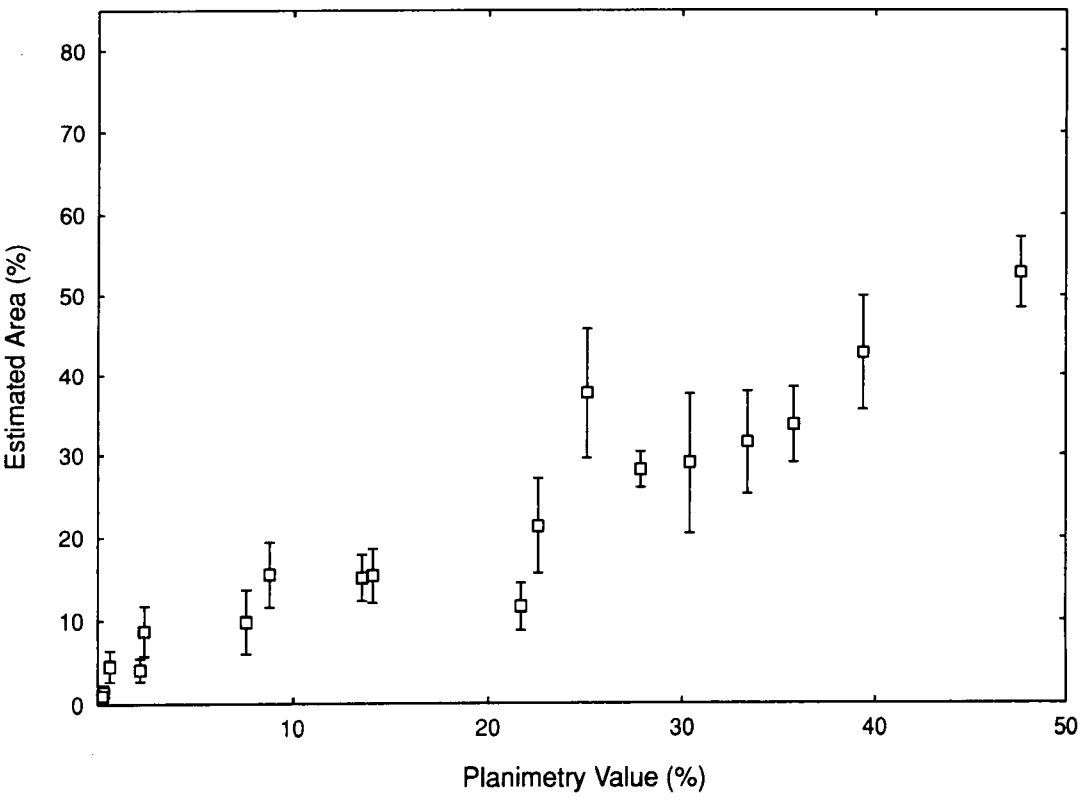


Table 2.4 shows the intercepts and slopes of the regression of estimated area on planimetric assessment for each subject. These regression lines are plotted in Figure 2.10 (visual group) and Figure 2.11 (SKINMAP group).

Table 2.4 Coefficients and residual errors from regressing estimated area on planimetric area for 16 subjects assessing 18 transparencies. The t-test for the intercept tests for a significant difference from zero; the t-test for the slope tests for a significant difference from 1 .

Subject	*Intercept*	*S.E.*	*t*	*sig*	*Slope*	*S.E.*	*t*	*sig*	*Residual SS*
SKINMAP group									
1	1.27	2.89	0.44	-	0.98	0.12	-0.17	-	926
2	0.44	2.42	0.18	-	0.92	0.10	-0.80	-	647
3	5.46	2.73	2.00	-	1.01	0.12	0.08	-	824
4	0.65	1.51	0.43	-	0.88	0.06	-2.00	-	253
5	1.47	2.72	0.54	-	1.06	0.12	0.50	-	819
6	2.85	1.80	1.58	-	0.95	0.08	-0.63	-	358
7	4.72	2.06	2.29	-	0.91	0.09	-1.00	-	472
8	3.41	1.92	1.78	-	0.97	0.08	-0.38	-	407
Visual group									
9	1.08	1.83	0.59	-	1.15	0.08	1.87	-	371
10	-3.50	2.77	-1.26	-	1.11	0.12	0.92	-	854
11	4.26	3.11	1.37	-	1.25	0.13	1.92	-	1072
12	2.93	4.13	0.71	-	1.42	0.18	2.33	-	1895
13	2.44	2.21	1.10	-	1.61	0.09	6.78	0.001	540
14	0.78	1.90	0.41	-	0.66	0.08	-4.25	0.05	401
15	-0.47	4.16	-0.11	-	1.46	0.18	2.26	-	1920
16	0.49	2.42	0.20	-	0.99	0.10	-0.10	-	651

The mean intercept for the visual group was 1.00 (SD 2.37) and for the SKINMAP group was 2.53 (1.89): there is no significant difference between these values (t=1.4, df=14). The mean slope for the visual group is 1.21 (0.30) and the mean slope for the SKINMAP group is 0.96 (0.058).

For this measure a simple t-test is not appropriate because the variances are not equal in each group. Therefore, calculating t' and applying the Welch-Satterthwaite approximation for calculating df' (Howell, 1987) gives t' =2.315 on 8 degrees of freedom, which is significant at the 0.05 level. Thus, the slopes are significantly different; however, in neither group is the slope significantly different from unity.

The difference in slopes can be better visualised if they are considered as deviations from the planimetric values, and these are plotted in Figures 2.12 and 2.13.

Figure 2.10 Regression of estimated area on planimetry for 8 raters using visual estimation on 18 slides

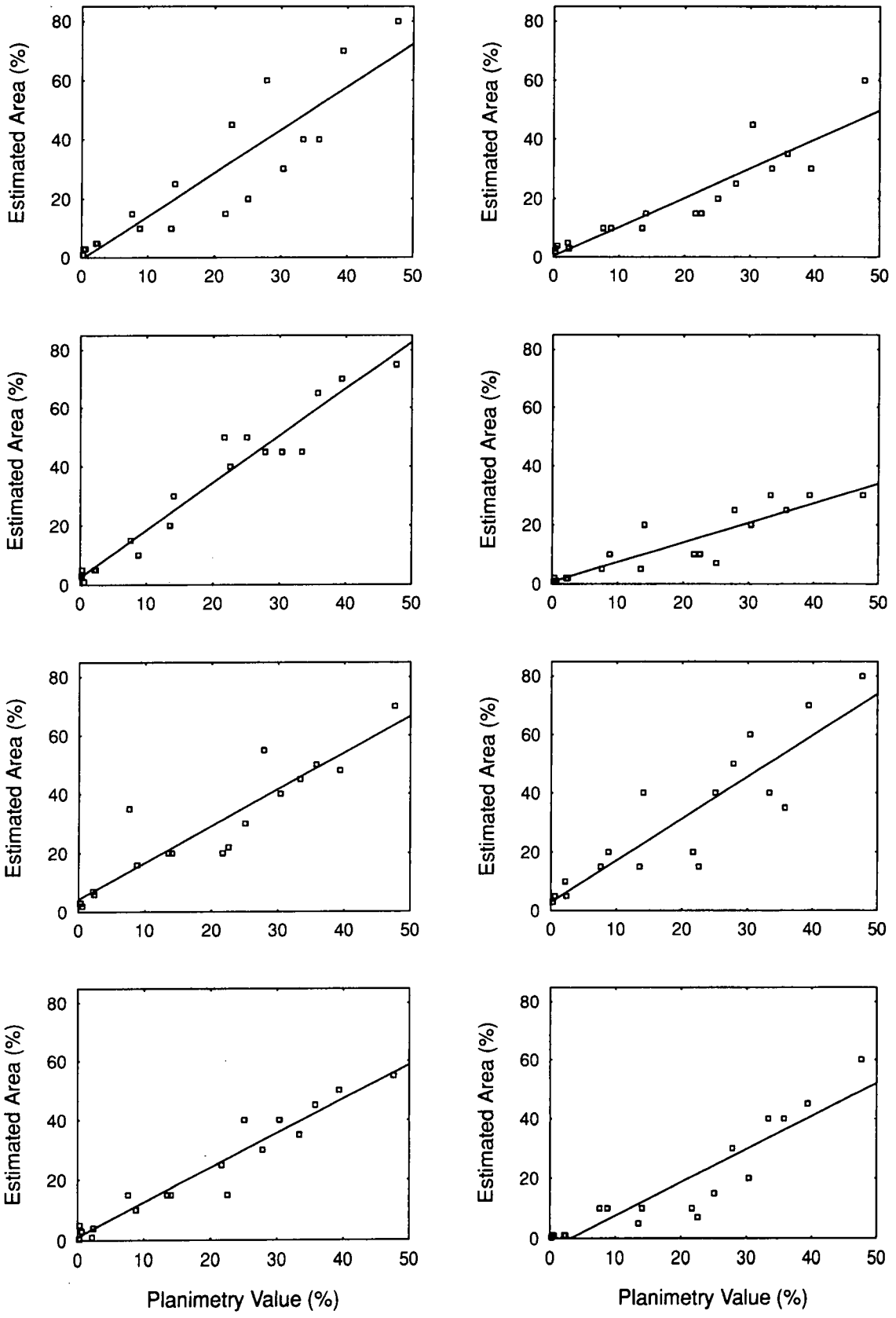


Figure 2.11 Regression of assessed area on planimetry for 8 raters using SKINMAP on 18 slides

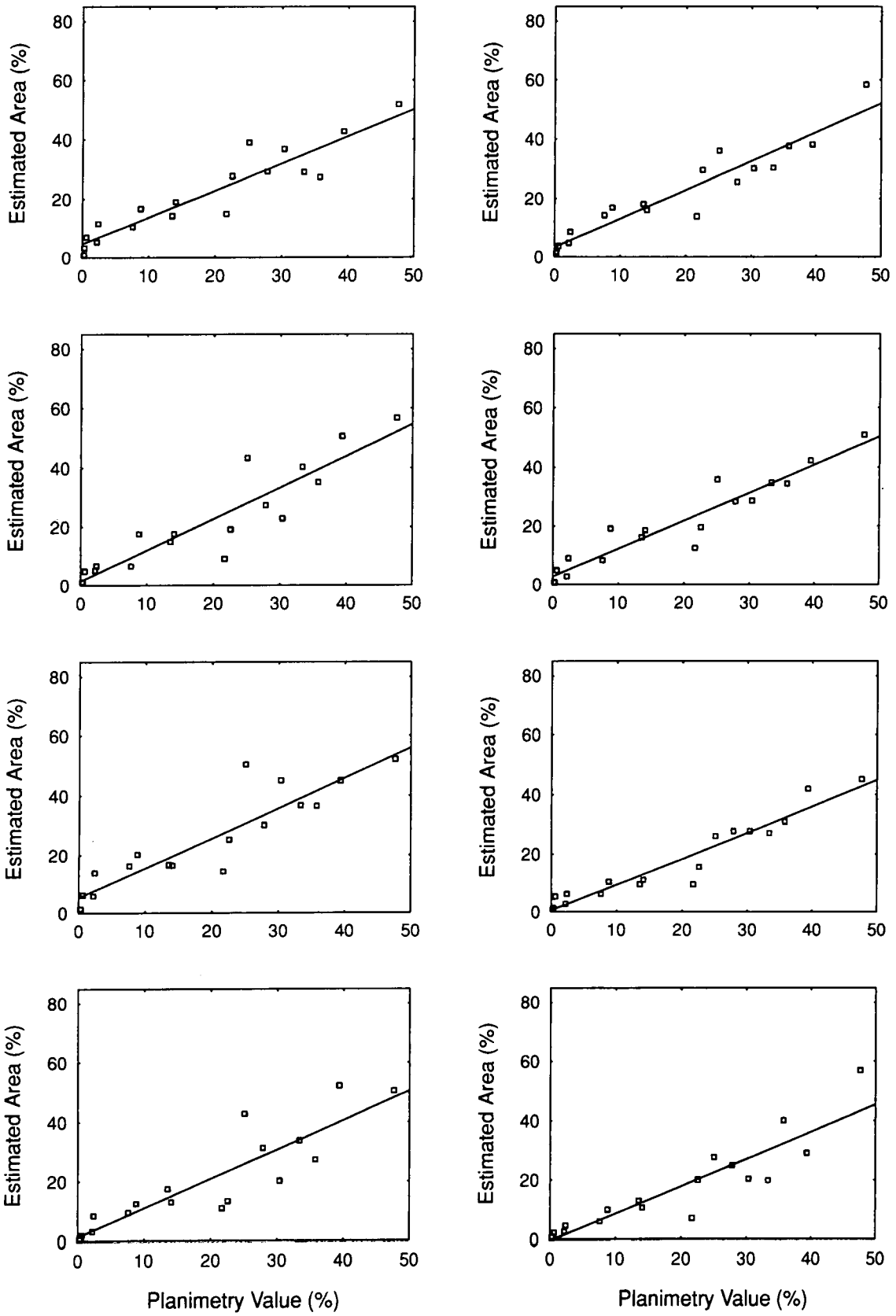


Figure 2.12 Regression of deviation from planimetry on planimetric values for 8 raters using visual estimation

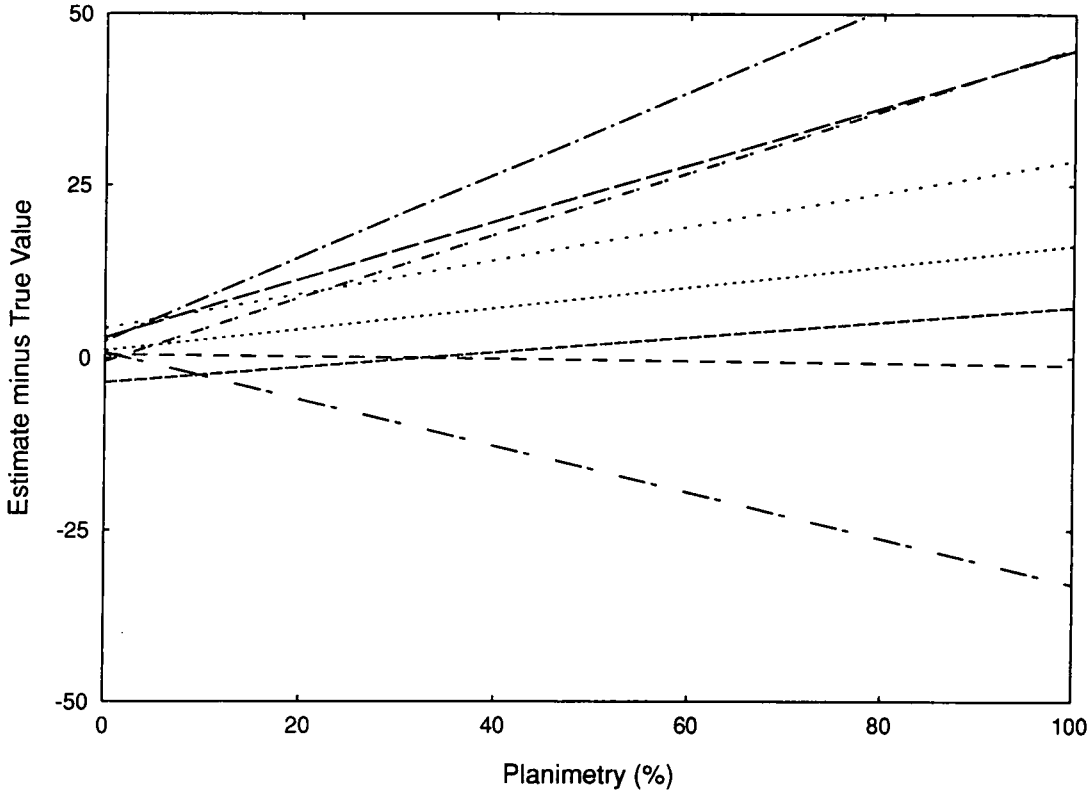


Figure 2.13 Regression of deviation from planimetry on planimetric values for 8 raters using SKINMAP

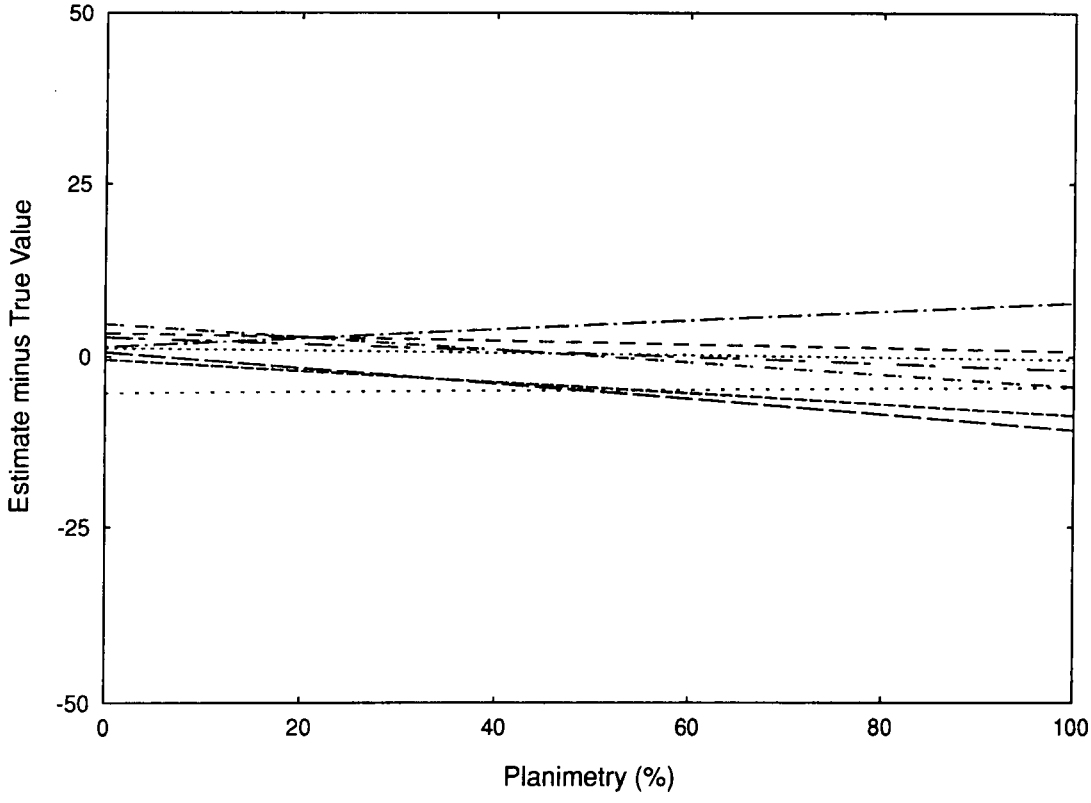
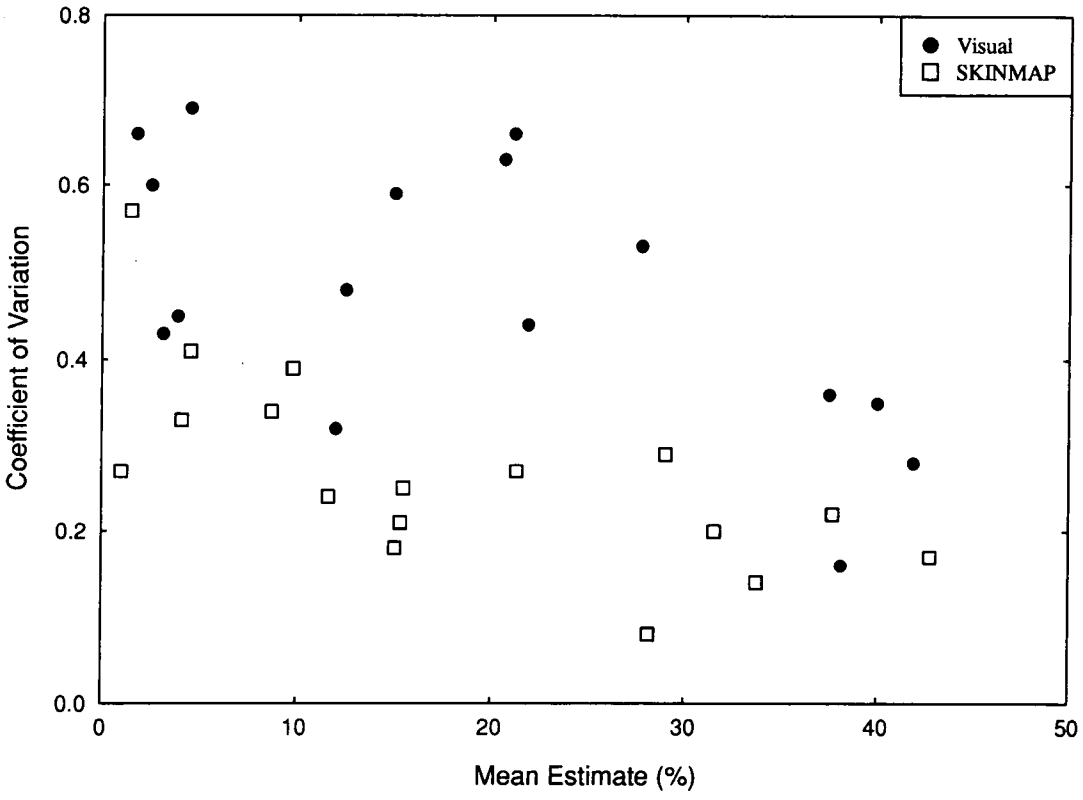


Figure 2.14 Coefficient of variation plotted against mean estimate for visual estimation and SKINMAP assessment of area on 18 transparencies.



The coefficients of variation for different levels of psoriasis coverage are plotted against mean estimate for each group in Figure 2.14. Inspection of this plot suggests that the visual group are less consistent in their estimates than the SKINMAP group, and indicates that variances are not proportional to means: no single summary statistic is appropriate.

In general, the residual sums of squares around the regression lines in the visual group are larger than in the SKINMAP group, as can be seen in Table 2.4. The largest *RSS* in the SKINMAP group is 926, while the largest *RSS* in the visual group is 1920.

To summarise, the mean intercepts for the regression of estimated area on planimetric value for visual estimation and SKINMAP assessment are not significantly different from each other. There was significant difference between mean slopes, though neither differed significantly from unity. When these slopes are plotted as deviations form planimetry, the wide variations in the visual group can be seen.

2.6 Discussion

As with Marks' group of clinicians (above), estimates of larger areas by both the visual group and the SKINMAP group tend to become more consistent as the true area increases

(that is, the coefficients of variation decrease), but this means that simple transformations cannot be applied to either set of data. It can also be seen however, that while the use of SKINMAP does not affect the fact that the variance of estimates of larger areas is relatively smaller than that of smaller areas (once the mean estimate has been taken into account), assessments by different subjects using SKINMAP will be closer to one another than by subjects estimating visually.

Examination of Table 2.4 reveals that the majority (6 out of 8) of subjects in the visual group tended to over-estimate larger areas (that is, the slope of the regression line was above 1), while the majority (again 6 out of 8) of SKINMAP assessments tended to slightly underestimate larger areas.

2.7 **Conclusions.**

Visual estimation of area of coverage is not accurate. Studies which have examined the perception of disk areas have shown that a simple "correction factor" does not work. Psoriasis lesions are discoid, thus visual estimation of area of coverage may not be accurate. Empirical evidence using a group of clinicians supports this. However, cartographic evidence suggests that individuals can *match* one disk with another accurately, even though they may not be able to assign an area value. A computer program, SKINMAP has been developed which allows patches to be positioned on body representations. The key task for the user, therefore, is to match disks rather than estimate areas - which is done by the program itself. Validation of SKINMAP shows it to produce more accurate and consistent area estimations when compared with planimetrically assessed transparencies of psoriasis.

The results presented in this chapter show that SKINMAP produces estimates of psoriasis coverage which give significantly more reliable information about area of coverage than existing methods, and SKINMAP will therefore be used to assess area of coverage as an independent variable in the remainder of the research reported in this thesis.

Chapter Three

Cross-sectional Investigation of Psychological Variables
in Psoriasis Out-patients and Controls

3.1 **Introduction.**

The studies reviewed in Chapter 1 suggest that psoriasis sufferers hospitalised for their condition are more depressed and anxious than controls groups, but the situation regarding psoriasis out-patients is less clear. For example, Hardy & Cotterill (1982) found psoriasis out-patients to be borderline depressed on the BDI, while Price *et al* (1991) found their groups scoring well within normal limits on the depression scale of the HADS. Price *et al* also found high anxiety scores in psoriasis outpatients. The main problem in evaluating the psychological state of psoriasis outpatients is the dearth of suitable studies: as noted in Chapter 1, most of the work with outpatients has used informal data collection techniques, or has not used adequate controls. Further, while anecdotal evidence suggests that psoriasis sufferers do not regard themselves as "ill" (e.g. Stankler 1981), they are, nevertheless, acutely aware of their physical symptoms (e.g. Jobling, 1976; Jowett & Ryan, 1985).

Much of the research on psychological problems associated with psoriasis reviewed in Chapter 1 has used hospital inpatients, but these account for only a small proportion of people who have psoriasis. Examination of the psychological state of psoriasis sufferers in general should involve a wider sampling frame of psoriasis sufferers in the community, so outpatients were used as the population from which the samples for the present research were drawn. This also means that any raised levels of anxiety will not be simply a consequence of hospitalisation. Derived from the general hypotheses summarised in Chapter 1, the specific aims of the present study are 1) to ascertain whether psoriasis outpatients have higher levels of depression and anxiety, and lower levels of self-esteem, than controls, 2) to ascertain whether psoriasis outpatients are more likely to be psychiatric "cases" than controls, 3) to assess their health status, and 4) if there are differences between psoriasis sufferers and controls on these variables, to examine relationships between them and age at onset, time since onset, and severity of psoriasis.

3.2 **Design**

The design of this study was cross-sectional, examining psychological variables in two matched groups. One group comprised psoriasis sufferers and the other, matched controls with no psoriasis and no other skin condition.

3.3 **Subjects**

Ethical permission was obtained from the North Durham Ethics Committee (Ref. EC275/90) to recruit subjects for the psoriasis group from the patient index at Dryburn Hospital, Durham. Outpatients over 16 years of age who had attended for treatment in

the years 1987 and 1988 were included in the initial sampling frame. However, because of possible conflict with other research projects, the Consultant Dermatologist stipulated that patients currently undergoing treatment could not be included.

3.4 **Procedure**

A letter was sent to each patient explaining the outline of the study and asking them to participate, together with a stamped, return envelope and a reply slip to be completed by the patient. If no reply had been received within four weeks a further letter was sent. A group of individuals not suffering from any skin condition was also recruited to be matched with the psoriasis group on age, sex, marital status and social class. This group was drawn from names and addresses of acquaintances provided by the psoriasis group. Since the two groups were to be matched, this technique has several advantages. Friends of subjects are more likely to be in the same social class, be of the same marital status and be of approximately the same age. Although this could not be guaranteed, it does increase the chances of obtaining samples who can be matched (O'Hara, 1989).

Upon receipt of the reply form, those subjects who agreed to participate were contacted by telephone, or by letter if they gave no telephone number, and a time arranged for a visit at their own homes. This location was chosen for several reasons. First, since one of the measures was to be state anxiety (that is, how anxious the subject is *at the present time*) it was felt that a familiar environment was more desirable than a hospital or University location. Second, since the groups comprised individuals with a wide age range living over a large geographical area, asking respondents to visit a single location may have caused problems associated with mobility or cost and consequently may have influenced response rates. Third, while the psoriasis group may have been quite motivated to participate in the study and been prepared to travel, the control group had less reason to participate and could not realistically be expected to travel.

In the psoriasis group, the severity of the condition was assessed using SKINMAP, and the age at onset of psoriasis recorded. Psoriasis on visible regions of the body was assessed, that is, arms, legs, hands and face. The coverage figures for individual body regions were combined to give a total figure. The remainder of the assessments were identical in both groups, comprising the questionnaires described below. The psoriasis group were also encouraged to talk informally about their condition and its effects on their lives.

3.5 **Questionnaires**

Demographic variables

Date of birth, age and sex were recorded for all subjects, together with marital status (defined as a categorical variable with two levels: married, or living with a partner; single, or not living with a partner) and social class as defined by the Office of Population Censuses and Surveys Classification of Occupations (1980). Social class was assessed on the occupation of the main wage-earner. If no occupant of the household was employed, previous occupation was used: all subjects were classified in this way.

Depression

The *Centre for Epidemiological Studies Depression Scale* (CES-D) used in this study was designed for assessing levels of depressive symptomatology in general populations, with the emphasis on the affective component of depression. It was not designed to measure the severity of already diagnosed depression, nor was it intended to provide clinical diagnosis of depression, although subsequent research has shown that application of an appropriate cutoff point to the scores does allow prediction of cases (Myers & Weissman, 1980). It is a 20 item structured interview or self-report questionnaire which returns a single score representing the level of depressive symptoms during the week prior to administration.

Each item is scored from 0 to 3, thus the theoretical range of scores is 0–60, where higher scores represent a larger number of symptoms reported, weighted by the frequency with which they have occurred during the specified time period. Radloff (1977) gives distribution data of CES-D scores for four populations and quotes a mean CES-D score in "normal" populations of between 7.9 and 9.3. In a psychiatric population this mean was 24.4. The distribution of scores is positively skewed in the normal population and approximately normally distributed in the psychiatric patient population. In a thorough and exhaustive validation of the CES-D, Husaini, Neff & Harrington (1979) demonstrated that a score of ≥17 provided the most appropriate cutoff point for "possible depression" and ≥23 for "probable depression".

Anxiety

The instrument for assessing anxiety in the present study was chosen on conceptual grounds. Spielberger's distinction between State and Trait anxiety has been discussed in Chapter 1. Spielberger and his associates (Spielberger, Gorsuch & Lushene, 1970) have developed and validated the *State Trait Anxiety Inventory* (STAI) for the assessment of these two factors, and this was used in the present study. They showed a median test-retest correlation of 0.7 for the trait anxiety scale but a test-retest correlation of only

0.33 for the state anxiety scale. This is to be expected since the state scale measures anxiety levels which are expected to fluctuate over time. The trait scale gave a median Cronbach's αcoefficient of 0.93 while the median for the state scale was 0.90 in a range of populations. This indicates that the questionnaire exhibits very high internal consistency. The authors also provide ample evidence that the scales correlate well with other anxiety measuring instruments.

It was also noted in Chapter 1 that anxiety can be conceptualised as comprising two distinct components: cognitive and somatic, and that analysis of individual response patterns has been useful in understanding the nature of anxiety reactions. Schwartz, Davidson & Goleman (1978) have developed the *Cognitive Somatic Anxiety Questionnaire* (CSAQ) which has subsequently been validated in a number of populations (e.g. Delmonte & Ryan, 1983; Tamaren *et al*, 1985; Crits-Cristoph, 1986; DeGood & Tait, 1987; Heimberg *et al*, 1987; Freedlan & Carney, 1988) and shown to discriminate these two components well. This questionnaire was used in the present study to examine the component nature of the anxiety experience.

Psychiatric morbidity

The literature review presented in Chapter 1 has suggested that more visible dermatologic conditions in general appear to be associated with a higher proportion of probable psychiatric "cases" (Hughes *et al*, 1983; Wessely & Lewis, 1989). The *General Health Questionnaire* (GHQ - Goldberg, 1976) was designed to identify possible and probable "cases" in a variety of populations. It returns an overall score which can be evaluated against cutoff criteria. The original version comprises 60 questions and scores have been shown in a variety of populations to correlate well with the Clinical Interview Schedule and the Present State Examination (correlations ranged from 0.76 to 0.80, Goldberg, 1976). The scaled version of the GHQ containing 28 items has been developed specifically for situations where more information is needed than a simple severity score to identify cases, and this instrument was used in the present study to examine in more detail the nature of any potential psychiatric problems. A total GHQ score is still obtained, but four sub-scale scores can also be calculated: somatic symptoms, anxiety and insomnia, social dysfunction, and severe depression.

Self-esteem

Robson (1989) has developed a self-report measure of self esteem with high validity and reliability. Split half correlation was 0.93 and Cronbach's $\alpha$was 0.89. Test-retest reliability over four weeks showed a correlation of global scores of 0.87 and the global score for this instrument correlated 0.85 with the widely used Rosenberg self-report

measure (Rosenberg, 1965), and 0.7 with clinical assessments by a group comprising four psychiatrists, three clinical psychologists and two psychotherapists. Since this instrument offers more detailed examination of the self-esteem construct than the Rosenberg scale, yet without the over-complexity of Marsh's instruments (e.g. Marsh *et al*, 1984), this self-report measure of self-esteem was employed in the present study to assess both global self-esteem and the relative contribution of individual components.

Perceptions of illness

Psoriasis is not generally a life-threatening or physically disabling disease: the main impact of the condition is on the sufferers life-styles. An exploratory investigation was therefore made of the self-perceptions of illness to see whether they could be related to other aspects of psoriasis.

Hunt *et al* (1981) have noted that perceived health status is "a key factor in aspects of adjustment to major episodes of illness" and have devised the *Nottingham Health Profile* (NHP), to measure perceived health status. Hunt, McKenna & McEwen (1989) in the manual for the NHP suggest that it can best be described as a "measure of distress in the physical, emotional and social domains" and that it is appropriate for use "to monitor changes in the subjective health of chronically ill patients over time" (p4)

The NHP has six scales measuring energy, pain, sleep, emotional reactions, social isolation, and physical mobility, and has been validated in a number of populations. Hunt *et al* (1980) tested the construct validity of this instrument in a group of elderly people with distinct physical illnesses and showed it capable of discriminating different chronic illnesses. A further validation study (Hunt *et al*, 1981), involved administering the NHP to a random sample of General Practice patients classified as "attenders" or "non-attenders": the rationale being that perceived health and clinic visits should be highly related. The authors found that NHP scores significantly discriminated attenders from non-attenders once age and sex had been controlled for. Further studies with the NHP using patients with osteoarthrosis (Hunt, McKenna & Williams, 1981) and peripheral vascular disease (Hunt *et al*, 1982) have shown each of the subscales to have acceptable reliability coefficients (0.77 to 0.88).

There is an optional section to the NHP that assesses which *areas* of the subject's life is affected. Hunt McKenna & McEwen (1989) advise that this section should not be used when the subject pool is drawn from a wide range of backgrounds: i.e. varying occupational and marital statuses. Since this is the case with the present group, only the first section of the NHP was used in the present study to examine perceived health status.

3.6 **Results**

The initial letter was sent to 152 psoriasis outpatients. Eighty eight replied, and of those, 57 said they would like to participate while 31 declined to take part. Ten letters were returned by the Post Office marked "Gone Away" and no further attempts were made to contact those patients. One letter was returned because the patient had died. Four weeks after the initial mailing, 53 reminder letters were posted. Of those, 13 patients agreed to participate, 11 declined, 3 were returned marked "Gone Away" and 26 did not respond. No further attempts were made to contact the non-responders. Thus, the overall response rate from letters which reached the patients was was 81%. Of those who received letters, 51% agreed to take part, giving 70 subjects in the psoriasis group.

The initial plan had been to recruit the control group by the same method, but it became clear very early on that the response rate from controls was extremely low. Controls were therefore telephoned or visited without an initial mailing, which by chance also resulted in a group comprising 70 subjects being recruited.

Age was calliper matched (Cochran, 1983) to ±5 years. That is, a control subject matched on age if they were within ±5 years of the psoriasis subject. Employing the strict matching criteria of sex, marital status, social class and age (±5 years) forced the rejection of 26 pairs of subjects. The matched group therefore comprised 57 subjects in each group: 21 pairs of males and 36 pairs of females. The demographic and descriptive variables for both groups are summarised in Table 3.1.

Table 3.1 Demographic and descriptive variables for psoriasis and control groups

	Full Sample		*Matched Sample*	
	Psoriasis	*Control*	*Psoriasis*	*Control*
Males	26	29	21	21
Females	44	41	36	36
Single (%)	16 (23)	15 (21)	14 (25)	14 (25)
Social Class				
1	0	0	0	0
2	14	21	12	12
3	34	28	27	27
4	12	12	9	9
5	10	9	9	9
Manual	33	30	26	26
Non-manual	37	40	31	31
Mean Age in years (SD)	43 (13.2)	41 (15.1)	42 (13.9)	41 (14.8)
Age range in years	17–74	18–70	17–74	18–70

There were no missing data for any subject since all the questionnaires were completed in the presence of the researcher and checked for errors.

3.6.1 **Psoriasis Group Characteristics**

Within the whole psoriasis group (n=70) the mean age at onset of the condition was 27 years (SD 17, range 2 to 67 years) and the mean time since onset was 16 years (14, 1 to 57). In the smaller group of matched subjects, the mean age at onset was the same but the mean time since onset was slightly lower at 15 years (13, 1 to 52). The mean area of coverage for the full psoriasis group was 4.1% (range 0 to 37.8%) and for the matched group 3.8% (0 to 37.8%). The distributions were positively skewed and the mean figures are included for comparison with other studies only. The median area of coverage for the full group was 1.4% (SIR 2.36) and for the matched group was also 1.4% (2.49)

3.6.2 **Effects of matching**

To assess the effectiveness of matching, the 57 pairs of subjects were coded by 56 dummy variables, which were then entered simultaneously into regression analyses for each dependent variable in turn. A significant *F* ratio indicates that a significant proportion of the total variance can be accounted for by the matching. A nonsignificant *F*-ratio indicates that the matching does not account for any significant amount of the total variance and implies that the matching process is redundant.

For those dependent variables where the matching had a significant effect in the whole matched sample (n=114), or the male or the female subsamples, all further analyses used only the matched pairs. For dependent variables where no matching effect was found, all 140 cases were used for further analysis so as to increase statistical power.

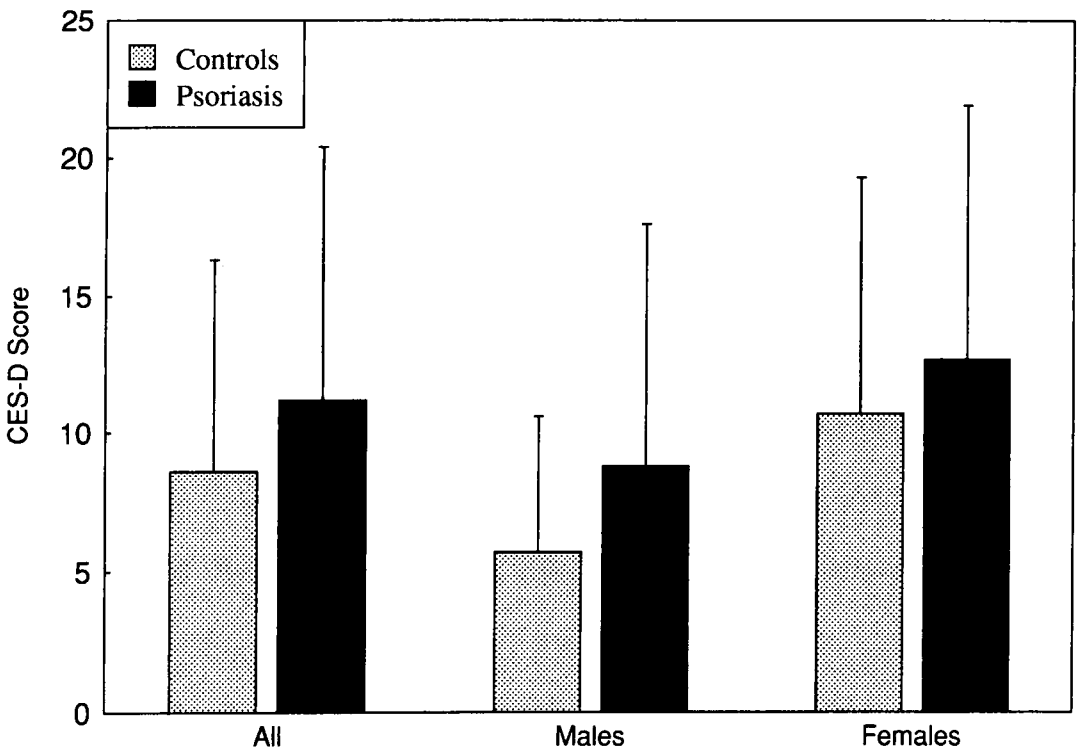
3.6.3 **Depression**

The matching explained none of the variance in the scores for this scale so the full sample of 140 subjects was used. The scores on the CES-D scale were moderately positively skewed so a square root transformation was used before t-tests were performed. The medians and semi-interquartile ranges are reported in Table 3.2. There was a significant difference between the control group and the psoriasis group (one-tailed) with the psoriasis group reporting more depressive symptoms than controls ($t=1.7, p<0.04$). There was no significant difference between groups in the male or female subsamples (Table 3.2) but in both the psoriasis and control groups the females scored higher than the males (Figure 3.1). Neither of the group medians reached the cutoff point of ≥17 defined as indicating possible depression (see above), but 18 individuals in the psoriasis group scored 17 or above, compared with 11 individuals in the control group.

TABLE 3.2 Summary of CES-D Depression scores for unmatched psoriasis (n=70) and control (n=70) groups. T-test is on square-root transformed scores

Sample	*Group*	*Median*	*SIR*	*Range*	*t*	*Sig p<*
All	Psoriasis	9.5	6.5	0–38	1.7	0.05
	Controls	6.5	5.0	0–33		
Males	Psoriasis	6.5	5.4	0–38	1.3	-
	Controls	5.0	2.8	0–19		
Female	Psoriasis	11.0	8.25	0–37	1.1	-
	Controls	8.0	6.5	0–33		

Figure 3.1 Depression scores (CES-D) for unmatched psoriasis (n=70) and control (n=70) groups



In the psoriasis group, none of the variance in depression scores was accounted for by any of the psoriasis-specific variables. No significant correlations were found between depression scores and age at onset (r=0.073), time since onset (0.094), or area of coverage (-0.022).

3.6.4 **Anxiety**

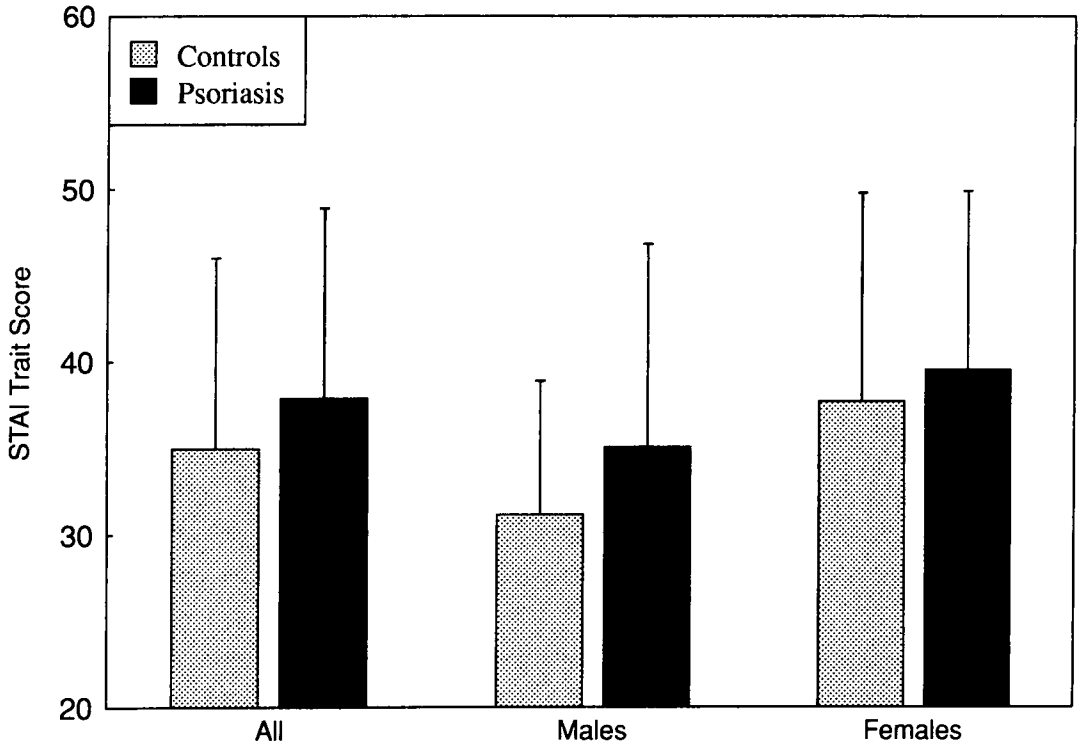
The State Trait Anxiety Inventory was administered such that the State form was completed first as recommended by Spielberger *et al* (1983). This ensures that the scale is not influenced by "the emotional climate that may be created if the T-scale is administered first" (p.4).

The scores on both the state anxiety scale and the trait anxiety scale of the STAI were moderately positively skewed, so a square root transformation was employed on all the data. None of the variance between groups was accounted for by the matching variables so the full sample of 140 subjects was used in all analyses. There were no significant differences between groups on the state anxiety scale for the full group or for males or females separately, but there was a significant difference between the full groups for trait anxiety ($t=1.65$, $p<0.05$, one-tailed), with the psoriasis group scoring higher than the control group (Table 3.3). The mean scores and SDs are presented in Figure 3.2. There were no significant correlations between trait anxiety scores and age at onset (r=0.11), time since onset (0.15), or area of coverage (0.068).

TABLE 3.3 Summary of Anxiety Scores (STAI) for unmatched psoriasis (n=70) and control (n=70) groups. T-test is on square-root transformed scores

Sample	*Group*	*Mean*	*SD*	*Range*	*t*	*Sig p<*
State Anxiety						
All	Psoriasis	32.1	10.0	20–58	0.06	-
	Controls	32.3	11.2	20–65		
Male	Psoriasis	28.5	9.0	20–58	–0.52	-
	Controls	29.3	7.5	20–46		
Female	Psoriasis	34.3	10.0	20–58	0.25	-
	Controls	34.5	12.9	20–65		
Trait Anxiety						
All	Psoriasis	37.9	11.0	20–64	1.65	0.05
	Controls	35.0	11.0	20–68		
Male	Psoriasis	35.1	11.7	20–64	1.33	-
	Controls	31.2	7.7	20–52		
Female	Psoriasis	39.5	10.4	20–61	0.94	-
	Controls	37.7	12.1	21–68		

Figure 3.2 Mean (SD) trait anxiety scores (STAI) for unmatched psoriasis (n=70) and control (n=70) groups



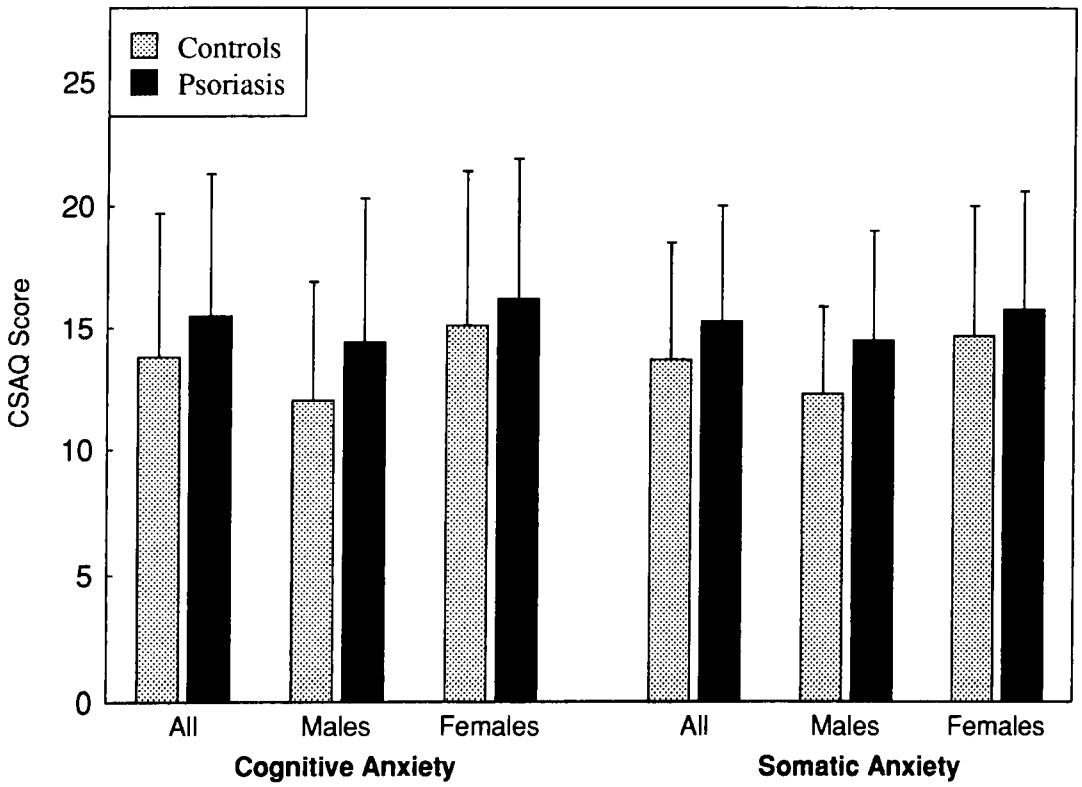
There were differences in the predicted direction between the psoriasis and control groups on both cognitive and somatic anxiety scales of the CSAQ, with the psoriasis group scoring higher than the control group (Table 3.4). While these differences were not statistically significant within the female subsample, the male psoriasis subsample did score significantly higher on both cognitive and somatic scales (Figure 3.3). Area of coverage did not account for any significant amount of variance on any of the scales, but age at onset significantly predicted somatic anxiety levels (Intercept=17.28, Slope=–0.075 (SE 0.033)) as did time since onset (13.86, 0.086 (0.039)).

There was no difference between groups in the mean *ratio* of cognitive to somatic anxiety symptoms: both group means were 1.03.

TABLE 3.4 Summary of CSAQ scores for unmatched psoriasis (n=70) and control (n=70) groups

Sample	*Group*	*Mean*	*SD*	*Range*	*t*	*Sig p<*
Cognitive Anxiety						
All	Psoriasis	15.5	5.8	7–28	1.73	0.05
	Controls	13.8	5.9	7–30		
Male	Psoriasis	14.4	5.9	7–28	1.64	0.054
	Controls	12.0	4.9	7–24		
Female	Psoriasis	16.2	5.7	7–27	0.85	-
	Controls	15.1	6.3	7–30		
Somatic Anxiety.						
All	Psoriasis	15.3	4.7	7–25	2.00	0.05
	Controls	13.7	4.8	7–31		
Male	Psoriasis	14.5	4.5	8–25	2.00	0.05
	Controls	12.3	3.6	7–21		
Female	Psoriasis	15.8	4.8	7–25	1.00	-
	Controls	14.7	5.3	7–31		

Figure 3.3 Mean (SD) cognitive and somatic anxiety (CSAQ) scores for unmatched psoriasis (n=70) and control (n=70) groups.



3.6.5 **Psychiatric morbidity**

The data from the General Health Questionnaire were very highly positively skewed with a large number of zero scores, making parametric analysis inappropriate. Using the matched pairs only, and the non-parametric Wilcoxon Signed-Ranks test to assess the difference between groups, there were no differences on either the total GHQ score or any of the subscales for the whole group or the male or female subsamples. There were 17 cases above the cutoff point of ≥5 in both the psoriasis and control groups. The psoriasis group median score was 2 (SIR 2.5) and the control group median was 1 (2.25).

3.6.6 **Self-esteem**

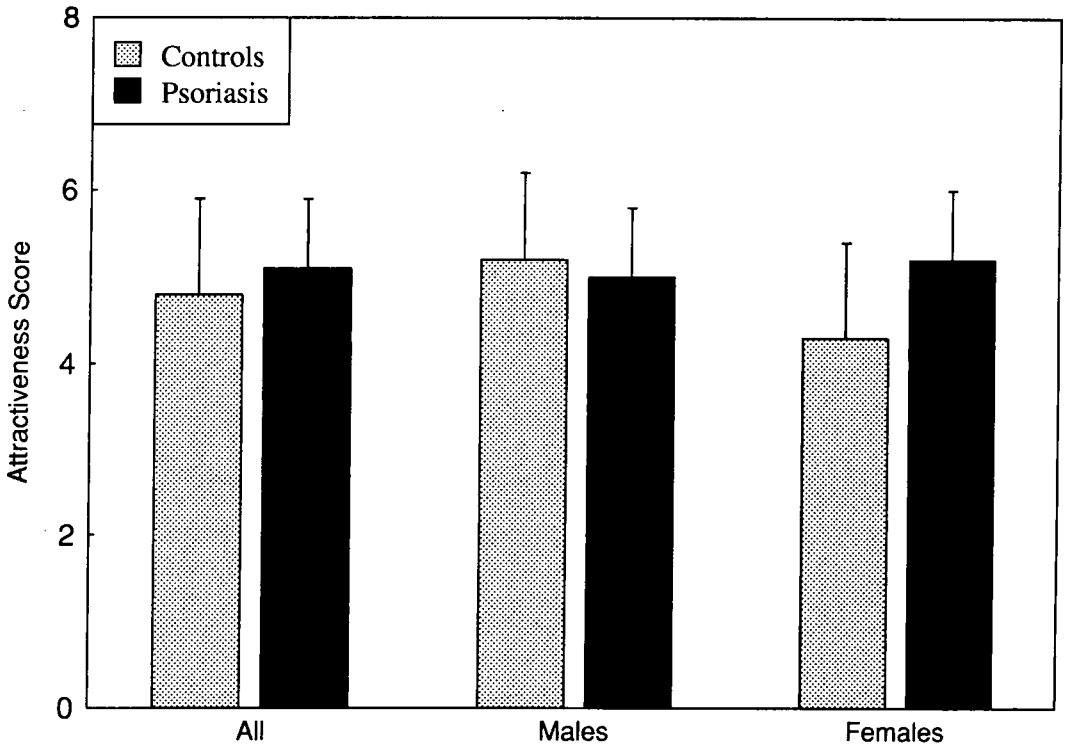
The matching variables did account for a significant amount of variance in the total SEQ score and the Value of Existence subscale. Therefore only the matched pairs were used in all the analyses of the results from this questionnaire. The means and standard deviations for the total SEQ scores are shown in Table 3.5. There were no significant differences between the psoriasis and controls groups on this scale. Since no previous research has reported on the components of self-esteem, analysis of the subscales must be considered exploratory at this stage and two-tailed significance levels used. The means and standard deviations are shown in Table A3.1 (Appendix 4). The only significant difference between the groups was on the attractiveness subscale for females ($t=2.5$, $p<0.02$) where the psoriasis group scored higher than controls (Figure 3.4).

None of the psoriasis-specific variables accounted for any of the variance in the attractiveness scores of females or in the full group.

TABLE 3.5 Summary of total SEQ scores for matched sample (n=114)

Sample	*Group*	*Mean*	*SD*	*Range*	*t*	*Sig*
All	Controls	136.8	26.8	69-186	0.2	-
	Psoriasis	137.7	22.2	99-195		
Male	Controls	141.8	21.7	105-186	0.3	-
	Psoriasis	144.1	20.1	105-195		
Female	Controls	133.9	29.3	69-186	0.1	-
	Psoriasis	134.1	22.8	99-187		

Figure 3.4 Mean self-esteem Attractiveness subscale scores for matched psoriasis (n=57) and control (n=57) groups



3.6.7 **Perceptions of illness.**

Distribution of the Nottingham Health Profile scores deviated considerably from normal, so Wilcoxon Matched-Pairs Signed Ranks Tests were used to assess any differences between the groups for the matched samples, in accordance with the recommendations of the test developers (Hunt *et al*, 1989). It was predicted that subjects would report lower subjective health status, so one-tailed tests were used throughout.

The median scores for each of the scales are shown in Table A3.2 (Appendix 4). There were no differences between the full groups, or the male and female subsamples on the energy, emotional reactions or physical mobility subscales. While there was no difference between the full groups on the social isolation subscale, there was a statistically significant difference between the males ($Z=-1.77, p<.04$) with the psoriasis group reporting more social isolation than controls, but this was not reflected in the female subsample. The full groups differed on the pain subscale ($Z=-1.84, p<.04$) with psoriasis subjects reporting more pain, but this was not reflected in the male or female subscale. The sleep subscale, which assesses sleep problems, showed significant differences between the full groups ($Z=-2.74, p<0.003$), the male subsample ($Z=-2.45, p<0.01$), and the female subsample ($Z=-1.7, p<0.05$). Thus, psoriasis sufferers reported more sleep problems than controls.

3.7 **Discussion.**

The overall response rate of 81% was better than expected. Unfortunately, it was not possible to ascertain the reasons for non-response, but it is certainly possible that those who chose not to reply, or those who chose to reply but not to participate, represented a distinct subgroup of sufferers which may have resulted in some biassing of the results. For example, those whose psoriasis was very mild may not have responded because they assumed only severe cases were required. Indeed, even though both the initial letter and the reminder stressed that all levels of psoriasis were of interest, several of the subjects who replied only to the reminder indicated that they had been interested in participating on receiving the initial letter, but that their psoriasis was so mild they assumed they would be of no use to the study. On the other had, it is equally possible that the non-respondents represented individuals who were so upset because of their condition that they did not feel they could discuss it with anyone.

The purpose of the matching was to control for any variance that the matching variables might contribute to the total scores. For example, depression has been shown to be correlated with social class (e.g. Brown & Harris, 1978), sex (e.g. Weissman & Klerman, 1977), and marital status (Radloff, 1975; Gove, 1972), while perceived health varies with social class, age and sex (Hunt *et al*, 1989). Therefore the individuals within each group were matched for sex, marital status, social class as defined by the Office of Population Censuses and Surveys Classification of Occupations (1980), and age in years. Age was calliper matched with a criterion of ±5 years (Cochran, 1983). Eighty-two percent of the sample matched on these criteria, giving 57 pairs. For the parametric analyses, where a significant amount of variance was accounted for by the 56 dummy variables coding for the match, all further analyses for that variable were computed after the matching variables had been entered. While the whole group of 70 subjects did not meet the strict matching requirements, there was no significant difference between the two full groups on any of the matching variables. Only the 57 matched pairs were used for the non-parametric analyses

The Centre for Epidemiological Studies Depression Scale (CES-D) was designed to assess those symptoms which may cluster together to form a depressive syndrome and hence deserve a diagnosis of "depression", but which may also exist as distinct depressive symptoms in the pre-depressed or non-depressed individual. Indeed, it is to be expected that most people will exhibit some of the symptoms to a greater or lesser extent, and it is only when a cumulative score over all the symptoms is evaluated that a decision can be made regarding a probable diagnosis of depression. The CES-D provides a continuous score with a theoretical range 0 to 60, where a score of ≥17 is generally used to indicate "possible depression" (Radloff, 1977).

While there is some clear evidence that psoriasis sufferers hospitalised for their condition are more depressed than controls, depression data for psoriasis outpatients is sparse (see Chapter 1). Hardy & Cotterill (1982) showed psoriatics more depressed than controls, while Price *et al* (1991) found no evidence of raised depression levels in their sample. In the present study the full psoriasis group and the male and female subgroups all scored higher on the CES-D than controls, but only the difference between the full groups was significant. Within the two groups, the median depression scores were both lower than the cutoff point of ≥17, but more psoriasis subjects scored above this (25.7%) than controls (15.7%). This supports the hypothesis that psoriasis outpatients have raised levels of depressive symptoms.

It was hypothesised that area of coverage would be correlated with depression scores, but this was not found to be the case. This is possibly because the levels of coverage were quite low, but it may also be the case that psoriasis sufferers are a group who are more depressed than controls *regardless* of the state of their psoriasis. Therefore, while no relationship has been found in the present study, no firm conclusions can be drawn about the possible link between depression and disease severity since psoriasis area of coverage did not encompass a large enough range. A further study, using psoriasis sufferers whose condition is more severe is needed to determine whether any relationship between area of coverage and depression exists, and this is reported in Chapter 5.

As with the depression data, while there is evidence that psoriasis inpatients are more anxious than controls, very few studies have examined anxiety levels in outpatients. The available evidence reviewed in Chapter 1 led to the hypothesis that sufferers have higher levels of anxiety than controls and that these levels are related to disease severity. In the case of trait anxiety this prediction was confirmed, with the psoriasis group scoring on average three points higher than controls, who in turn scored close to the reported "normal" mean. This difference between groups is small but statistically significant, and supports the hypothesis that having psoriasis leads to anxiety.

There were no differences between the groups in the case of state anxiety. There may be several reasons for this. First, individuals were interviewed in this study in the familiar, and presumably relatively unthreatening environment of their own home. Second, the psoriasis group was interviewed by a researcher who himself has psoriasis which may have minimised the perceived likelihood of feeling negatively evaluated. Indeed, once this fact was revealed to the patients, there was a quite noticeable change in attitude, from apprehension and hiding of the psoriasis to a more open and inquisitive response. The norm cited on the state anxiety scale for male working adults is 35.7 (SD 10.4) and

for female working adults is 35.2 (10.6) and on the trait anxiety scale 34.9 (9.2) and 34.8 (9.2) (Spielberger *et al*, 1983). Thus, both psoriasis and control groups score below average on the state scale and the psoriasis group scores above average on the trait scale.

Again, perhaps because of the low levels of disease severity, no relationship was found between disease-specific variables and anxiety. Therefore, psoriasis sufferers are more prone to experiencing anxiety than controls, but the association with disease severity requires further investigation using subjects with more severe psoriasis to ascertain whether raised anxiety can be related to psoriasis severity. This will also be examined in Chapter 5.

However, while the STAI is designed to assess *levels* of anxiety, the Cognitive-Somatic Anxiety Questionnaire (CSAQ) is specifically directed at the *manifestation* of anxious symptoms, and to assessing whether these present primarily through a cognitive channel, a somatic channel, or both. The results of this study showed that the psoriasis and control groups differed in their cognitive manifestations of anxiety (e.g. difficulty in concentrating, indecisiveness, anxiety-provoking thoughts and pictures), and somatic anxiety (e.g. increased heart rate, tense stomach, perspiration) with the psoriasis group scoring higher on both scales. There are at least two ways of interpreting this. Psoriasis sufferers may indeed experience more frequent or more intense reactions to anxiety than controls. On the other hand, it may be that the CSAQ is simply measuring *awareness* of symptoms, as in Dooley and Finlay's (1989) study which showed psoriatic females to be more conscious of their bodies than controls. In the present study, it was hypothesised that reported levels of cognitive and somatic symptoms would be related to the severity of the condition but this was found not to be the case. Both scores were, however, related to age at onset and time since onset, with earlier age at onset associated with higher scores and longer since onset associated with higher scores also.

In respect of psychiatric "cases", the results of the present study do not support the findings of Hughes *et al* (1983) or Wessely & Lewis (1989), both of whom found higher numbers of probable "cases" in their samples. This is probably because their samples comprised a range of other skin conditions as well as psoriasis, some of which are definitely related to psychiatric problems (e.g. *dermatitis artefacta*). There is no evidence therefore from the present research that psoriasis sufferers are more likely to be psychiatric "cases" than non-sufferers.

The only difference between the groups on the Self Esteem Questionnaire was between females for the Attractiveness subscale. Interestingly, the psoriasis females scored significantly *higher* than the controls, suggesting that they considered themselves *more* attractive than non-sufferers. However, none of the variance in this subscale was accounted for by any of the psoriasis specific variables and a further study is therefore needed using psoriasis sufferers whose condition is more widespread to confirm that there is no relationship between disease severity and scores on this scale. This will be reported in Chapter 5.

A great deal of information and insight was gained through informal discussions with the psoriasis group. Since much of this forms the basis for the next study, the details are reported in Chapter 4. However, formal data about perceived health status were available from the Nottingham Health Profile results. The clearest difference between the groups was on the sleep subscale, which assesses sleep problems, where psoriasis sufferers had more problems than non-sufferers. Unfortunately, the NHP was not designed to specify exactly what these sleep problems are, so a more detailed sleep questionnaire was used in the study described in Chapter 5 to further investigate these findings.

Pain is not usually thought of as a symptom of psoriasis, yet the two groups differed significantly on this NHP subscale, with psoriasis sufferers reporting more pain than non-sufferers. Again, the NHP is not designed to quantify pain, other than giving an indication of broad problem areas. However, this finding is interesting and has not previously been reported. While it may be that the pain reported on the NHP can be accounted for as itch, it may also be the case that some psoriasis sufferers experience pain specific to their condition over and above the general discomfort caused by itching skin. The study reported in Chapter 5 examines this possibility in more detail and looks at qualitative pain description in psoriasis.

3.8 **Conclusions.**

This initial study has shown that while psoriasis outpatients are more depressed and are more prone to experience anxiety (which presents through both cognitive and somatic channels) than controls, they do not constitute a group which would be classified as possible psychiatric "cases" on the General Health Questionnaire. There are differences in self-esteem, particularly with respect to self-evaluated attractiveness, and psoriasis sufferers have problems with their sleep and problems with pain that have hitherto not been considered part of the experience of psoriasis. However, it has not been possible to establish any link between disease severity and these factors. This may have been because the psoriasis was generally quite mild in the majority of the subjects, but it may

also be that psoriasis sufferers are a group who are more anxious and more depressed than non-sufferers irrespective of the state of their psoriasis.

Two areas of further study suggest themselves from these results. First, the nature of this study has been cross-sectional, but given that psoriasis is often phasic in its course, can the psychological variables examined so far be related to fluctuations in the severity of the condition *within* patients? A prospective study would provide data on levels of psychological variables with subjects effectively acting as their own controls, thus base levels would be taken into account and *change* in area of coverage could be related directly to *change* in psychological variables such as depression and anxiety. This will be examined in the study reported in Chapter 5. Second, it became clear from informal discussions with sufferers in the present study that there is a considerable body of lay knowledge about psoriasis that may be instrumental in guiding perceptions about the disease and about its probable course. At the time of writing, this knowledge had not been examined systematically, and it may be useful in forming a more complete picture of the psychological states associated with psoriasis, as well as guiding treatment practices. Examination of lay beliefs and knowledge about psoriasis is reported in Chapter 4.

Chapter Four

Patients' Beliefs and Knowledge about Psoriasis

4.1 **Introduction**

In addition to its formal aims, the previous study gave some insight into the worries and concerns of the psoriatic population under investigation. In conversation with the sufferers, several areas of concern emerged. Indeed, it became increasingly clear that there is a body of lay beliefs about psoriasis, some of which reflect established facts quite accurately, but more of which does not.

The information in the following section was not collected in any standard format, and must therefore be interpreted with care. Nonetheless, it is of use in outlining beliefs that appear to be common to many of the subjects, and it forms the basis of the interview schedule reported later in this chapter, which investigates those beliefs more formally.

4.2 **Findings from informal discussions with psoriasis patients**

First, subjects were unclear as to the actual nature of their condition. Several people inquired about a link between skin cancer and psoriasis, while several others sought clarification of a link between asthma and psoriasis. Many held to the belief that psoriasis may be caused by an allergic reaction, mostly to food or workplace substances.

None reported that the physiology of psoriasis - exactly what happens to psoriatic skin - had been explained to them, even at a basic level. Regarding information about the probable course of their illness, many indicated that they had been told by their doctors that their condition was incurable. This may influence motivation to continue with treatment. There was widespread evidence of non-compliance with prescribed treatment, and many of the patients reported having tried a variety of medicaments, all with little or no effect, and all with considerable personal discomfort and mess. Reports of trying non-medical treatments were given by quite a large proportion of the sample, usually in guarded tones to begin with. However, the efficacy of these "alternative" treatments was reported with often quite remarkable forcefulness. (One woman insisted that St Michael's - and *only* St Michael's - vegetable oil rubbed on the lesions daily was the only effective treatment). Many had tried alternative treatments ranging from hypnosis to brewer's yeast.

Stankler (1981) suggested that it takes about ten years to "come to terms" with having psoriasis. The willingness to try often quite inappropriate alternative "cures" can be interpreted as an indicator of the strong desire the sufferers have to clear their psoriasis. Many expressed anticipation that the treatments they tried would not work, but at the same time indicated that they would continue trying anything that stood even the remotest chance of effecting relief.

While most were aware of some vague genetic link, many, particularly women, showed distinct signs of worry about their children "catching" psoriasis from them. It was not clear whether they were referring to passing on the disease through a hereditary mechanism, or though infection.

The majority of sufferers insisted, without prompting, that their psoriasis worsened at times of worry. For those who reported a seasonal fluctuation in severity, most indicated an improvement in the summer. There was no indication of feeling "unclean" or of the so-called "leper complex" reported in the literature (e.g. Updike, 1980).

While the level of satisfaction with the care of specialist clinicians (i.e. the Hospital Dermatologists and Nursing staff) was high, GPs (in general, and sometimes by name) were often spontaneously and forcefully condemned for their apparent inability to prescribe any effective treatments, or more often for their ways of talking to patients.

In summary then, informal conversations during the previous study suggested that patients do not possess basic factual knowledge about their condition, self-medicate with varying success, and in general are dissatisfied with their primary health care.

4.3 **The study of lay medical beliefs and knowledge**

There is an extensive body of literature concerned with lay medical and health beliefs, and a large number of studies which have attempted to quantify or explain how those beliefs relate to knowledge about various medical conditions. Beliefs about illness held by individuals guide how they react to their condition and how they manage their treatment so are important in planning care and predicting the course of illnesses. Bishop (1987) has argued that people do not respond to disease symptoms *per se* but rather they interpret those symptoms within their own framework before they decide the most appropriate course of action to deal with the symptoms - whether to seek medical advice, to use medical treatment they already possess, to seek alternative treatment, or to do nothing. While noting that the concept of symptom-interpretation is generally accepted by other theorists, Bishop argues that the precise attributional processes postulated are generally categorised *a priori* and reflect more the preconceptions of the researcher than issues important to the patient. In an attempt to overcome these shortcomings, Bishop employed the methodology of multidimensional scaling and cluster analysis to evaluate lay conceptions of illness symptoms.

He found that 'disruption to activities' was one of the most important aspects of illness symptoms for both men and women in deciding how severe a condition was. Further,

the perceived *cause* of the symptom was crucial in determining what the patient said they would do about it. Interestingly, patients who perceived the cause of a symptom to be physical indicated that they would seek medical help, while those who perceived the symptom's cause to be psychogenic indicated that they would tend to self-medicate. These findings have implications for the present study. Psoriasis sufferers report major disruption to their everyday activities (e.g. Jobling, 1976; Jowett & Ryan, 1985) which, under Bishop's model would suggest that they were likely to perceive their symptoms as severe. Furthermore, many patients see worry or stress as the cause of the relapse of their symptoms (e.g. Farber & Nall, 1974). Again under Bishop's model this would suggest that psoriasis patients are quite likely to self-medicate in preference to seeking medical advice. Bishop also reported that when self-care was examined separately, although perceived psychogenic symptoms were likely to result in self-medication, the *level* of self-medication was likely to be very low, i.e. symptoms were quite likely not to be treated *at all*. So it may be that the perceived cause of psoriasis symptoms results in relatively low levels of treatment compliance.

Bishop (1991) has extended these ideas to look at how non-sufferers perceive various diseases, and more particularly at their willingness to interact with individuals who have certain diseases. Not surprisingly, he found that diseases perceived as contagious resulted in a lower likelihood of interaction than those perceived as non-contagious. As one would expect, the true nature of the condition (contagious or not) was completely irrelevant: only the perception was important. Bishop also found that people would tend to interact more with a person whose disease was perceived as being hereditary than with someone whose disease was not perceived as being hereditary (although it must be noted that diseases rated as hereditary were also generally rated as not contagious). Bishop found however, that the perceived *severity* of the condition did not predict willingness to interact. Once again this has implications for psoriasis sufferers, whose condition is sometimes perceived as contagious but also hereditary. Under Bishops' model, lay beliefs about psoriasis, both on the part of sufferers themselves and the general public, should result in lower interpersonal contact. This, of course, may be compounded, as Strauss (1975) has suggested, by the nature of the treatment of psoriasis, in that it is generally intrusive either in looks or in odour.

Perceptions of illness have been examined in more detail by several authors, and the methodologies employed are discussed below. One interesting variation was by Furnham (1989) who examined lay attributions for the *cure* of various so-called "psychosomatic" conditions, one of which was dermatitis. He had subjects rate the importance of

a variety of factors in overcoming the specified illnesses. In the case of dermatitis, subjects believed that the most important influences on overcoming the condition were "how embarrassed a person feels about having the problem", "how damaging the problems is to a person's self-worth and self-esteem", and "how much eliminating the problem would please others", all of which comprised the factor labelled "social consequences". Since none of his sample were suffering from dermatitis this can be taken to represent a general belief about the condition. Psoriasis has been categorised as a psychosomatic illness (see Chapter 1) and in the sense that they are both skin conditions of broadly similar appearance, it is reasonable to suggest that these beliefs may also apply to psoriasis, though this was not examined explicitly by Furnham.

The acquisition of knowledge and the development of beliefs about a condition from the sufferers point of view is not simply a matter of internalising presented information. Steptoe *et al* (1991) have pursued the concept of information seeking as a coping style in health related situations and suggest that there are two main types of information-seeking behaviour: "monitoring" and "blunting" (Miller & Mangan, 1983). "Monitoring" refers to the strategy of requesting and actively searching for information about the particular condition, whereas "blunting" refers to the strategy of actively *avoiding* information about the condition. Steptoe & O'Sullivan (1986) found that, while blunters said they were satisfied with the information they had about their condition (cancer), and thought they had a good understanding of it, when their knowledge was tested, their knowledge was actually quite poor. Monitors also thought they had a good understanding of their condition, but in contrast, their knowledge scores were relatively high. Steptoe & O'Sullivan interpret this as representing two coping styles. Thus, poor knowledge of a medical condition may not reflect the quality of the sources of information so much as the willingness to acquire that knowledge.

While much research has concentrated on doctor-patient communication as a source of information for the patient, Frankel, Davison & Smith (1991) argue that patients get information from a variety of sources. Thus, they define this "lay epidemiology" as arising from informal conversations with peer groups and others in the individual's social network, television and magazines and other media productions as well as, and along side, medical encounters. These sources guide the knowledge base and belief system of the individual. Other authors argue the same point. Helman (1990) for example, stresses that the *whole* of society provides a framework within which illness is interpreted and, notes that the medical profession exist within that framework also. Thus, traditional 'medical' sources of knowledge stem not only from the concepts embodied in the biomedical model of western medicine, but are also interpreted through

the "filter" of social knowledge. Helman cites two studies by Elliot-Binns (1973, 1986) which confirm that knowledge and beliefs about health are drawn from a wide variety of sources: 95% of a sample of 1000 GP patients received advice on their condition *before* consulting the doctor, with an average number of sources of advice of 2.3.

In summary, beliefs about illness affect patients' help-seeking behaviour and the way that non-sufferers interact with patients. Beliefs about the factors influencing the cure of psychosomatic diseases in the case of dermatitis place "social consequences" as most important. The acquisition of knowledge upon which beliefs are based is mediated by the coping style adopted by patients, and knowledge is obtained from a wide variety of sources, other than doctors and other health-care workers.

4.3.1 **Methodological issues**

There have been many studies which have attempted to measure the knowledge and beliefs of patients in a variety of illnesses following differing methodologies. For example, the study by Steptoe *et al* (1991) referred to above, asked five questions about cancer and scored the answers as zero for "don't know", 1 for an incomplete answer and 2 for a complete answer. This gave rise to a score between 0 and 10 which was used as their measure of knowledge about cancer. While this technique does provide a score that can be related to other variables, it does so at the expense of more detailed analysis of patient responses. Several other studies provide better examples of methodologies used in patient knowledge surveys.

One widely used instrument is the Test of Patient Knowledge developed by Etzwiler (1962) and Collier (Collier and Etzwiler, 1971) which was designed to assess changes in knowledge about diabetes following instruction programmes. Although the psychometric properties of this instrument are well documented and impressive (e.g. Garrard *et al*, 1987) there are two problems as far as using this in the present study are concerned. First, the questionnaire was explicitly designed for testing knowledge about diabetes and is not a general instrument. Second, and perhaps more important, Donovan, Blake & Fleming (1989) have noted that the multiple-choice format (used in the Patient Knowledge Test) may not in fact measure *knowledge* in the sense of understanding, but rather may measure it only in the restricted sense of recalling certain facts. Many questionnaires follow this format, perhaps most notably the Kidney Disease Questionnaire developed recently by Devins *et al* (1990), and the Patient Knowledge Questionnaire developed for use with rheumatoid arthritis by Hill *et al* (1991).

This criticism can also be levelled to some extent at the 51 item questionnaire used by Rubinfeld *et al* (1988) in their large study of Asthma knowledge in Melbourne, Australia. Their questionnaire required true/false/uncertain responses and was scored such that correct answers received a score of 1 while incorrect or uncertain answers received a score of zero. Thus, respondents were required only to choose options, not to express their own views. There was no further probing to elaborate on where knowledge originated or on what basis guesses were made. The main purpose of this questionnaire was to generate a "knowledge score" which could be used in conjunction with other variables. Like the two psoriasis knowledge questionnaires discussed below, this approach emphasises accuracy but does not examine in any detail the nature of *in*accurate knowledge, which is a valuable source of data in evaluating the best sources of information.

Shevde & Panagopoulos (1991) approached this issue from a slightly different angle in their survey of 800 patients' knowledge and attitudes about anesthesia. They interviewed prospective patients with a mixture of Likert scaled and open-ended questions in order to elicit a range of information about patients' beliefs. Rather than generating a "knowledge score", they concentrated on more descriptive analysis of their data and were able to provide more in-depth insights into patient concerns and beliefs.

This approach was developed further by Donovan & Blake (1992) who used a tape-recorded semi-structured interview administered in the patients' own homes, which was later transcribed and analysed following the principles of grounded theory (Glaser & Strauss, 1965). The grounded theory approach involves extracting themes from the data by repeated reading, rather than applying a pre-defined conceptual framework. The theory, in Glaser & Strauss' terms, is 'grounded' in the data, rather than in the preconceptions of the researcher. Perhaps the most important finding of Donovan & Blake's study as far as the present research is concerned, was that almost all the respondents expressed a desire for more information about their condition, its treatment, side-effects and prognosis. The use of semi-structured interviews for eliciting this type of information is common in ethnomethodological research and provides a vehicle through which data can be obtained which expresses issues important to the respondent, while retaining the basic structure which is necessary if individuals are to be considered as a group.

The semi-structured interview (tape recorded and later transcribed) was therefore chosen as the most appropriate method for investigating patients' beliefs about psoriasis. The structure of the interviews was derived from two sources. The informal conversations with psoriasis sufferers from the study reported in Chapter 3 and outlined earlier in the present chapter coupled with previous research on patients beliefs in psoriasis

provided a valuable basis for identifying issues of likely concern to patients. Thus, the framework was generated primarily by psoriasis patients themselves. Second, Kleinman (1980) has proposed the use of what he has termed "explanatory models" which can be used as a framework for interpreting patients' (and indeed doctors') beliefs about illness. Kleinman stresses that the explanatory model is distinct from a general health belief model (which is embedded in local cultures) because it relates specifically to a single episode of ill-health: thus one individual may use several independent explanatory models as a framework for different illnesses. The explanatory model is simply a categorising system which comprises five areas: *etiology, symptoms, pathophysiology, course of the illness,* and *treatment.*

To summarise, while some approaches to the measurement of patient knowledge and beliefs have concentrated on generating "knowledge scores", more detailed information can be obtained by using semi-structured interviews which allow the respondents to express their own views. The structure for the interviews in the present study comes from informal discussions with subjects in the previous study, and is guided by the general format of the explanatory model proposed by Kleinman (1980).

4.4 **Previous studies of lay knowledge of psoriasis.**

Ray Jobling has written eloquently about the sociological implications of having psoriasis from a patient's point of view (e.g. Jobling, 1977). He describes what can often be "a long career of arduous patienthood" (p73) in terms of the personal adjustment and adaptation to chronic psoriasis which can influence every aspect of the patient's life: psychological and social, as well as financial. He also notes that the stigma attached to psoriasis (either real or imagined) can have effects on significant others in the patients environment. For example, bed linen is often stained by psoriasis treaments - hanging out this stained linen for all to see can be a cause of embarrassment. Further, Jobling implies that the medical profession may subtly use patient knowledge (or rather, *lack* of knowledge) to legitimise their inability to treat the condition. That is to say, they may blame failure of the psoriasis to respond on the patient not understanding and following treatment instructions rather than on their own inability to prescribe effective treatment.

Jobling, who is a psoriasis sufferer himself, gives useful descriptions of his own personal experiences. However, more generalisable data on the connection between patient knowledge and disease state can be obtained by examining experiences reported in a wider sample. Only two studies have attempted to examine in a standardised way the knowledge that psoriasis sufferers have about their condition. Burton & Thompson (1976) examined beliefs about skin conditions in a group of 151 mixed dermatology

outpatients, but unfortunately they did not attempt to distinguish the replies of patients suffering from different conditions. Their questionnaire was designed to assess what patients thought about doctors, the type of treatment they were receiving, and whether they had experienced any difficulty in their normal routines because of their condition, and did not inquire about beliefs that patients have about the condition itself. On these grounds, Burton & Thompson's study is of little value in guiding the current investigation, although it may be useful in elaboration of Jobling's (1977) assertion that psoriasis sufferers' relationships with the medical profession change over time, not only in the sense of the patient becoming more active in the understanding of their condition, but also in the sense that changing doctors may necessitate a change in ideaology for the patient (from a biomedical standpoint, for example, to a "psychologistic" approach).

Of more value however, is Savin's (1970) earlier attempt to document beliefs about psoriasis in a series of 58 sufferers. He instructed them to *"Please write down the things that you think most important about psoriasis; in particular things that you think doctors ought to know about."*, and found that patients tended to write mostly about the worry caused by psoriasis and the self-consciousness and embarrassment that they associated with this. A small number of patients (12%) thought that psoriasis could spread around the body by an auto-infection mechanism, but only one patient thought that other people could "catch" psoriasis. The other main theme of responses was criticism of treatment and treatment-prescribing practices.

Both of these studies provide limited information on patients' beliefs about psoriasis, but also suffer from severe shortcomings. The main problem is that the instructions for both studies stated that they were interested in beliefs about the condition that may be of interest to *doctors*, rather than first ascertaining those areas which were of interest to the *patients*. More recently, and after the present study had been undertaken, Lanigan & Farber (1990) published results from an investigation of patients' knowledge of psoriasis with a sample of 52 psoriasis outpatients compared with 17 other dermatology outpatients in America, and yet more recently still Lanigan and Layton (1991) employed the same questionnaire with a sample of 108 outpatients in Britain. Their results will be discussed in comparison with the present findings later in this chapter.

4.5 **Study of the beliefs and knowledge of psoriasis outpatients**

Ethical permission for this study was granted by the North Durham Ethics Committee (Ref EC290/91).

4.5.1 **Subjects**

During the previous study, a note was made when subjects indicated that they would be willing to participate in further research. Forty six subjects were identified in this way and contacted again. Of those, 37 agreed to participate further and were visited again at their own homes. There were 11 males and 26 females; the ratio of males to females is not significantly different from that found in the previous study ($\chi^2 = 0.536$) nor is the mean age of 43.8 years (SD 14.5) significantly different.

4.5.2 **Procedure**

Based on the issues raised by subjects in the previous study, an interview schedule was devised (Appendix 3) comprising both open and closed questions which probed knowledge and beliefs about a range of issues concerned with psoriasis. These fell into four main areas corresponding to four of Kleinman's explanatory model categories (above): *etiology, pathophysiology, course of sickness,* and *treatment*, plus a category of more specific knowledge about the condition, and a general area exploring sources of knowledge about psoriasis. The interview schedule was administered by the researcher to each of the subjects, and the responses tape recorded and subsequently transcribed. Respondents were encouraged to talk as much as they liked, and where a range of fixed response options was available, these were presented to the respondent on a printed card. The purpose of the interview was explained to each subject and their consent obtained for the session to be recorded prior to the start of the interview. Each subject was asked to sign a declaration that they did not object to the interview being taped, provided all references that might identify them or others were removed in transcription and the tape erased (Appendix 3). A written record of responses was also made at the time of the interview for use in the event of a poor recording or equipment failure. The interviews lasted between 20 and 45 mins and were transcribed by the researcher.

4.5.3 **Analysis**

Analyses of the interview responses are presented below in the following manner. The precise wording of each question is followed by a rationale for formulating a "correct" response. Where two question numbers appear together, the second refers to an open-ended supplementary question. The main purpose of this study was to provide *qualitative* information on patients beliefs about psoriasis. When the question was closed, the numbers of subjects answering in each category are reported. When the question was

open, the scripts were content analysed and a summary of the results reported. The content analysis procedure (following the recommendations of Krippendorff, 1980), involved reading through all the answers to each question and extracting common themes. Each answer was then re-read and the frequency of references to each of the themes noted. Where other themes became apparent on the second reading, the process was repeated for all responses. Scripts were then re-checked against the extracted themes. These themes, together with the frequency of occurrence are presented verbatim below.

4.5.4 **Results**

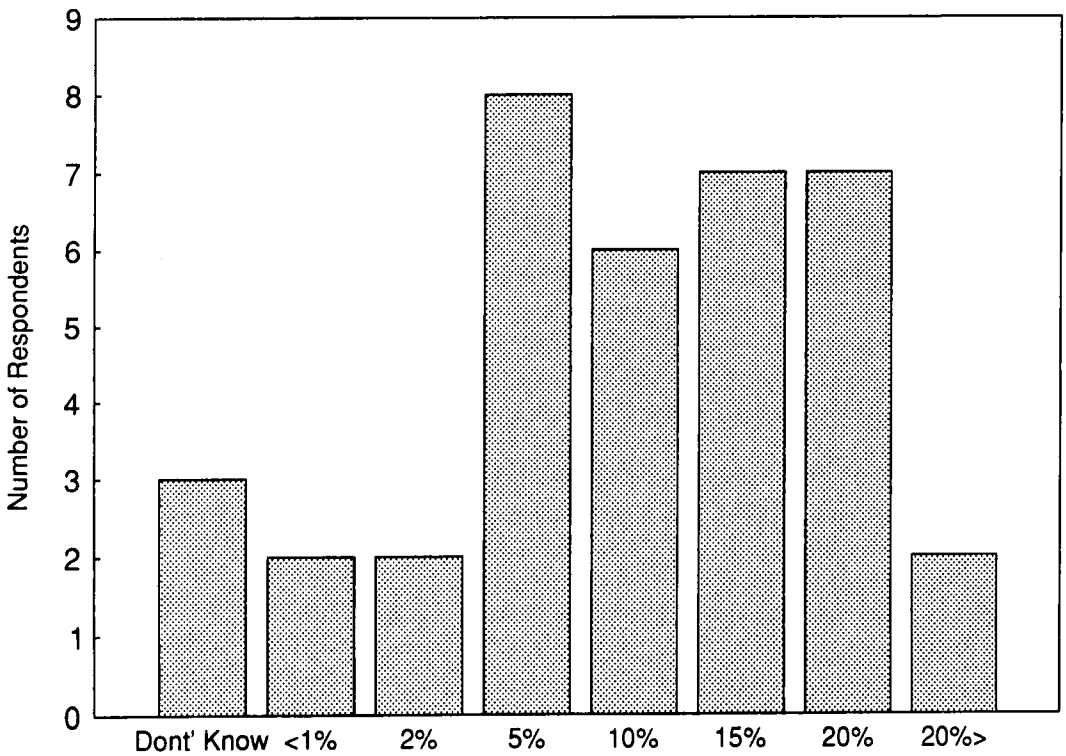
Question 1

What proportion of people in Britain would you estimate are currently suffering from psoriasis?

The point prevalence of psoriasis in Caucasian races is between 1% and 3% (Chapter 1).

Eight percent of the sample answered that they did not know the prevalence of psoriasis. Of those that did indicate a figure, the trend was to overestimate the true prevalence: 22% of respondents suggested a prevalence of 5% while 60% suggested a prevalence of ≥10% (Figure 4.1).

Figure 4.1 Respondents estimates of the prevalence of psoriasis in Britain



The question which must be answered is where these estimates originate. It may be that respondents were aware of another prevalence figure often quoted, that is, the rate of presentation at dermatology clinics. There have been several studies which estimated the prevalence of psoriasis using patients attending both "free" clinics and private practice clinics as a sampling frame. Table 4.1 lists the results of "free" hospital and clinic studies, and suggests a mean presentation rate of 5.2%. This figure is the percentage of patients presenting at dermatology clinics, not true prevalence in the population.

TABLE 4.1 Prevalence of Psoriasis in Hospital/Clinic Studies.

Country	*Sample*	*Frequency*	*Source*
Scotland	68,400	4.8%	Ratzer(1969)
Northern Ireland	14,231	5.5%	Hall & Burrows (1968)
Germany	13,075	7.4%	Ross (1971)
Spain	4,600	3.7%	Romaguera (1980)

However, another explanation may be that respondents were simply guessing at a figure and not basing their estimate on specific knowledge. Although the answers were chosen from options on a card, an analysis of the supplementary language used by respondents can clarify the strategies they were employing. Content analysis of the responses revealed 7 distinct patterns (Table 4.2). Response patterns 1 to 5 suggest a guess rather than recall, while response pattern 6 suggests recalled figures rather than a guess.

TABLE 4.2 Frequency of Response Phrases to Question 1.

Pattern	*Response*	*Frequency*
1	Definite reason to indicate a guess	6
2	"I would say ... "	15
3	"I would think..."	2
4	"Probably ..."	4
5	"Maybe..."	4
6	"I think its about..."	2
7	No additional language used	9

Question 2 & 3

Do you think psoriasis affects equal numbers of men and women, or do you think one sex is affected in greater numbers than the other?

The epidemiological data analysed in Chapter 1 suggests that psoriasis is more prevalent in males than females. Data from hospital and clinic studies presented in Table 4.3

show the numbers of males and females presenting with psoriasis, and males do out-number females, but in 4 hospitals there are more women than men. Unfortunately, the authors do not give total numbers of males and females in the population, so no firm conclusions can be drawn about true differences.

The most frequent response to this question (68%) was that men and women suffer in equal numbers. However, while 8% thought more men suffered than women and 5% had no ideas at all, 19% thought that women are affected in greater numbers than men. A supplementary question was asked to ascertain on what grounds any estimate of in-equality might be based. One respondent had no idea why they thought more women suffered than men, while five respondents indicated that they based their estimate on personal knowledge of other sufferers. Of the remaining four, two that indicated women suffering more than men said they thought it was because women are more anxious than men or worry more, while two thought men suffered more than women because men are under more stress than women.

TABLE 4.3 Sex Ratio of Psoriasis in Hospital Presentations.

Source	*Total*	*Male*	*(%)*	*Female*	*(%)*
Ratzer	3,323	1917	(58)	1406	(42)
Ross	963	453	(47)	510	(53)
Hoede	1,437	833	(58)	604	(42)
Steinberg	464	251	(54)	213	(46)
Braun-Falco	536	257	(48)	279	(52)
Farber	5,600	2562	(46)	3038	(54)
Powell	406	150	(37)	256	(63)
Andressen	2,994	1677	(56)	1317	(44)
TOTAL	15,723	8100	(52)	7623	(48)

Question 4 & 5

Do you think children are any more or less likely to develop psoriasis if one of their parents already has it?

Dr B ter Haar (in Mier & van de Kerkhof, 1986) has produced a table of approximate risks of getting psoriasis for a given familial occurrence, reprinted here as Table 4.4.

Table 4.4 Risk of Psoriasis (Mier & van de Kerkhof, 1986).

Family members with psoriasis	*Risk %*
Both parents	50
One parent, one sib	16
No parents, two sibs	16
One parent, no sibs	10
No parents, one sib	7
Second-degree relatives	4
Third-degree relatives	1-2

Dr ter Haar quotes a risk of 10% if one parent has psoriasis, the correct answer is that there is an increased risk if one or more parent has psoriasis.

The responses to this question indicate that about 65% believed that psoriasis may be hereditary. Of those who answered that they thought children were more likely to get psoriasis if one parent already has it (24/37), all gave as the reason that it "runs in families" or used the word "hereditary" in their responses.

Question 6 & 7

Do you think there are any particular groups of people who get psoriasis more frequently than others?

Lomholt's (1963) extensive survey of psoriasis in the Faroe Islands found no particular occupational groups overrepresented, but Hellgren (1967) did report a comparatively high prevalence in people who work with animals or animal products, or people whose work brings them into contact with hair (e.g. hairdressers). Hellgren did not, however, provide information on the occupational status of these individuals at the time of onset, so it is not possible to assess his findings in relation to the present question. Other evidence (e.g. Ingram, 1954) would suggest that no occupational or socioeconomic group is overrepresented.

In estimating whether certain groups of people are more likely to get psoriasis, 11% of the present sample said they did not know, 57% said no, but 32% did indicate a group or groups that they thought were at risk. Suggestions about the nature of these groups are presented in Table 4.5

Table 4.5 Groups perceived to be at risk of psoriasis

Group	*Reason*
Teaching profession	- No reason
People in our zone of the world	- No reason
People who work in dusty places	- Drying out of skin
Cleaners	- Allergic reactions
Unemployed	- Worry
Nervous people	- Worry
Businessmen	- Stress
People in stressful jobs	- Stress

Question 8 & 9

Do you think psoriasis can be affected by how clean a person is?

There is no evidence to suggest that psoriasis is directly affected by cleanliness. None of the respondents thought psoriasis could be affected by how clean a person is, but one did not know.

Question 10 & 11

Do you think it's possible for psoriasis to be infectious - that is, under certain circumstances can someone else catch psoriasis from you?

There is no evidence at all that psoriasis is infectious. However, pustular psoriasis is characterised by (benign) pus filled papules which might give the impression of co-existent infection. None of the patients seen in the present study suffered from pustular psoriasis, which is relatively uncommon (Mier & van de Kerkhof, 1986).

The majority (92%) felt that psoriasis was not infectious under any circumstances. Of the three people who thought it could be infectious, one said, "When it weeps, when you scratch it and it bleeds, I'd be wary of anybody touching then. But when it's dry, I'd say it's harmless", while another thought it could be infectious if it bleeds too much. One said there is a certain type of psoriasis that can be infectious which is quite distinct from "the ordinary most common one", which may be a reference to pustular psoriasis.

Question 12 & 13

In people who already suffer from psoriasis, do you think it is sometimes possible for psoriasis to develop at the site of cuts or scratches?

Psoriasis may form at the site of skin trauma; an effect generally referred to as the *Koebner phenomenon* (Koebner, 1877) or isomorphic response. Pedace *et al* (1969) demonstrated that the histological and clinical features of psoriasis induced by a Koebner reaction are identical to those which occur spontaneously. There is no doubt

therefore that the lesion produced by the Koebner phenomenon is psoriasis. Powles *et al* (1990) noted that the epidermis must be damaged before psoriasis lesions will develop.

The Koebner response appears to be 'all or nothing'; that is, a sufferer either will react with a Koebner reaction in all cases of skin trauma, or will not react at all. There is an incubation period of several days (Pedace reported a mean of 16.8 days) before the psoriatic lesion begins to appear.

Eyre & Krueger (1982) demonstrated a reverse Koebner phenomenon, by which psoriasis lesions cleared following a shave biopsy, and they note that this response too is 'all or nothing'. Predicting Koebner reactions was not linked to disease activity, i.e. whether or not new plaques are forming, but the authors suggested that susceptibility to the Koebner phenomenon changes as the disease progresses. They do not present any evidence to support this claim. Out of 24 subjects, they reported 25% with positive Koebner reaction and 67% with a positive reverse Koebner reaction, but the two reactions never appeared together in the same patient.

The respondents in the present study were divided as to whether they thought this reaction could happen. Three said they did not know, but 52% said they thought it could not happen while 41% said they thought it could.

Of those who said they thought it could happen, the reasons given were varied. Of the explanations offered, one said that psoriasis bleeds easily, and the bleeding spreads it; one thought that the healing process continues too long, transforming a normal scar into psoriasis; one respondent thought that open wounds 'attract' psoriasis and another thought a wound lets germs in. One respondent said she did not treat any skin trauma any more because it was the *treatment* that brought on the psoriasis. The rest had no explanation or said they answered from personal experience.

Question 14 & 15

Do you think pregnancy can affect psoriasis at all?

The literature suggests that there is a tendency for psoriasis to improve during pregnancy, but that this does not happen in every case. Lomholt (1963) reported 38% of 70 pregnant women experiencing a remission or improvement during their pregnancy, while 4% experienced exacerbation. This was replicated by Braun-Falco (1972) who reported 40% of 85 improving against 17% worsening, and by Farber & Nall (1974) who reported 32% of 1018 improving and 18% worsening. However, in these three studies, 57%, 40% and 50% respectively reported no change during pregnancy. None of

the authors give figures for controls over the same period, so although this evidence is suggestive, it is not possible to conclude that pregnancy and psoriasis are related.

In the present study, 35% said they did not know whether pregnancy affects psoriasis while 19% said it definitely does not affect it. Of the 46% who said pregnancy does affect psoriasis, four thought it would make it worse and twelve thought it would make it better: one thought it would depend on the individual whether it made it worse or better. When questioned on the reason for pregnancy affecting psoriasis the responses fall into two categories: physical changes and psychological factors (Table 4.6).

Table 4.6 Reasons for psoriasis changing during pregnancy.

Physical Changes:	*Number of responses*
Hormonal changes	6
'Change in your body'	1
'Change in your blood'	1
Extra vitamins in the body	1
Psychological Factors:	
'The anxiety factor'	1
Feeling less stressed when pregnant	1
Not worried about how you look when you are pregnant	1
Worry that the child will get psoriasis if you have it bad at the time of birth	1
Both	
Pregnancy 'upsets your whole mental attitude or body'	1

Question 16 & 17

In general, do you think having psoriasis affects the way people sleep?

The results of the Nottingham Health Profile - Sleep subscale used in the previous study indicated that sleep disturbance is a factor in psoriasis. This has been supported by Finlay *et al* (1990) who found a mean score on the Sickness Impact Profile (Sleep and Rest Subscale) of 15.2 in psoriatics compared with 0.25 in healthy controls, indicating significantly more sleep problems in psoriasis sufferers.

The present sample were divided as to whether they thought psoriasis affects sleep. Only one respondent had no idea, while 46% said it does not affect sleep and 51% said it does. One respondent noted that he slept badly when his psoriasis was bad, but observed that he was usually under stress at those times and could not therefore attribute poor sleep to psoriasis alone. Other reasons given for psoriasis affecting sleep were:

getting warmed up (3 references); being under stress, worrying more at night, or being worried about the psoriasis (9 references); itchiness (14 references).

Question 18

Can you tell me what actually happens to the skin in psoriasis?

It was not expected that the respondents would have precise knowledge of the physiological changes that occur in psoriatic lesions. Is was expected however, that they could exhibit some broad grasp of the biological mechanisms.

Quite a high percentage (35%) of respondents said they had no idea what happens to the skin in psoriasis. Of those who thought they knew (n=24), 19 gave an explanation which was correct, while 5 gave an explanation which was not correct. Of these five, two thought that the skin 'just dried up', a further two thought there was 'too much blood' in the plaque area, and one said the skin is 'damaged'.

Question 19 & 20

Do you think psoriasis may be an early form of any other disease?

Arthropathy has been shown to occur in psoriasis patients more frequently than non-sufferers. Leczinsky (1948) reported 6.8% prevalence of arthritis in psoriatics (n=543) compared with 0.7% in the same number of non-psoriatic controls. Other than this possible link, psoriasis is not an early form of any other disease.

The majority of respondents (73%) did not think psoriasis was an early form of any other disease. Two said they did not know. Of the 22% who thought it was, one thought it might turn into skin cancer, one thought it was an early form of eczema, one that it had caused her rheumatism, and five that it was an early form of arthritis. However, several respondents indicated that they had previously thought it was an early form of another disease, but had subsequently changed their minds. Specifically, two had thought it could turn into skin cancer, and a further two that it was an early form of arthritis.

Question 21

In your opinion, is psoriasis a member of a 'family' of illnesses?

This question was included to examine further how sufferers located their condition within the spectrum of other illnesses: the particular terminology was used because it had been used in the previous study, where several subjects had spontaneously indicated that they thought psoriasis was as member of a 'family' of illnesses but had not been specifically questioned as to the extent or nature of that 'family'.

The most important source for associating psoriasis with other conditions is Lindegard (1986), who reported on diseases associated with psoriasis in 372 sufferers drawn from the Gothenburg Population Cohort Study. Within the full group, he found significant statistical associations between psoriasis and viral infections, hypertension, alcoholism, pneumonia, liver cirrhosis, urticaria, and rheumatoid arthritis. Psoriasis in males was associated with iritis and ankylosing spondylitis, while in females it was associated with lung cancer, diabetes, obesity, myocardial infarction, and asthma.

Two respondents indicated that they had no ideas on this question while 19 (51%) said they did not think psoriasis was a member of a 'family' of illnesses. Of the remaining 43%, Table 4.7 lists the frequency of diseases mentioned.

Table 4.7 Diseases mentioned as members of the same 'family' as psoriasis

Disease	*No of Responses*
Eczema	11
Asthma	6
"Other skin diseases"	5
Arthritis/Rheumatoid arthritis	3
"Nerves"	3
Chicken Pox	2
Hay fever	2
Shingles	1
"Children's rashes"	1

Question 23 & 24

Once a person has psoriasis, do you think it's possible that it will ever clear away and not come back?

The answer to this question is problematic, since there are no data on those patients who simply do not return to the hospital or GP. Nevertheless, there are data on remissions (both spontaneous and following treatment) which suggest that psoriasis may remain clear for as long as 54 years (Farber & Nall, 1974). It is likely therefore that some patients whose psoriasis goes into remission later in life may remain clear for the rest of their lives.

Only one respondent said they did not know the answer to this question, and only one said that it might be possible "if you can get rid of every last bit". Of the remaining 95%, many answered in very definite terms that even if psoriasis could be cleared it would not remain cleared.

Question 25 & 26

Are there any sorts of diet that are particularly good for psoriasis?

Dietary manipulation for psoriasis is not usually a feature of mainstream medical treatments, and psoriasis is not thought to be caused by food allergy.

The responses to this question were mixed, with 22% saying they did not know whether particular sorts of diet were good for psoriasis, 38% saying there were no special diets, and 40% saying there were. Of the 15 respondents who said diet could help psoriasis, the specific foods are listed in Table 4.8. It should be noted that the respondents were only asked whether they had heard of any diets, not whether they had tried them or were currently using a diet to treat their psoriasis.

Table 4.8 Foods claimed by psoriasis sufferers to influence their condition (numbers indicate respondents who mentioned each item).

Foods to avoid:		*Foods causing allergic reactions:*	
Acidic or spicy foods	3		
Citrus fruit	3	Fruit	1
Oranges			
Vitamin C			
Milk and Dairy produce	2		
Fat and fatty foods	3		
Alcohol	1		
Chocolate	2	Chocolate & Sweet things	3
Tomatoes	1		
Tinned foods	1		
Foods good for psoriasis:		*Special diets for psoriasis:*	
Fish	1	Cod and carrots	1
Raw vegetables & Natural foods	2	Rice	1
Fresh fruit	2	Low protein	1

In addition, one respondent noted that healthy eating helps any disease, and one said that any *change* of diet would help psoriasis.

Question 27

Are all the ointments prescribed by the doctor for psoriasis really just different strengths of the same thing?

Topical treatments available on prescription are derived from quite different and distinct pharmacological basic agents, reflected in the categories of Table 4.9, but several subjects in the previous study had indicated that they thought treatments were "pretty much all the same stuff".

In response to this question, the majority (54%) thought that all ointments prescribed by the doctor for psoriasis are just different strengths of the same thing. A total of 5 respondents (14%) did not know.

Question 28

Respondents were asked to name as many treatments as they could that were available from a doctor or from the hospital for psoriasis. The treatments named are listed in Table 4.9. The final category of unknown treatments comprises treatments mentioned as available from medical sources but which cannot be classified according to the British National Formulary (1990).

The respondents were also asked to rate how effective they thought each treatment was and whether or not they had used it. The ratings were chosen from a prepared card with the categories:

Don't know
Doesn't work at all
Works a little
Works a moderate amount
Works quite well
Works very well

scored from 0 ("Don't know") to 5 ("Works very well"). Of a total of 125 ratings of treatments, 16 (12.8%) were made on treatments that subjects had heard about but never used. Subjects named a median of 3 treatments each, (range 0 to 12), and had personally used at some point a median of 3 treatments each (range 0 to 10). The mean rating for treatments that had been used was 3.08 (SD 1.38) and the mean estimate of the effectiveness of treatments that had never been used was 3.75 (1.44).

Question 29

Respondents were also asked to name as many treatments as they could that they would *not* get from a doctor or from the hospital. The treatments named are listed in Table 4.10. Of a total of 75 ratings, 21 (28%) were made on untried treatments. Respondents named a median of 2 treatments each (range 0 to 10), and had used a median of 1 treatment (range 0 to 10). The mean rating of effectiveness for treatments that had been tried was 2.65 (SD 1.53) and the mean estimated effectiveness of treatments that had not been used was 2.52 (1.37).

TABLE 4.9 Treatments for psoriasis reported to be available from medical sources

	No. of subjects who had heard of this treatment	*No. of subjects who had heard of this treatment and had also used it*	*Mean Rating if treatment used*	*Mean Rating if treatment not used*
STEROIDS				
Betnovate cream or	12	12	2.9	-
Betnovate 1 in 4	1	1	4.0	-
Betnovate scalp	6	6	3.3	-
'Cortisone creams'	1	1	2.0	-
Dermovate	9	8	3.3	4.0
Diprosalic (ointment	5	5	2.6	-
Eumovate	1	1	5.0	-
Nerisone oily cream	1	1	1.0	-
'Steroid cream'	1	1	2.0	-
'Steroid tablet'	1	1	5.0	-
Stiedex	1	1	4.0	-
Synalar	1	1	5.0	-
EMOLLIENTS AND SHAMPOOS				
Oilatum emollient	1	1	4.0	-
Polytar shampoo	3	3	3.0	-
'Shampoos'	1	1	4.0	-
Sudocrem	1	1	3.0	-
Unguentum Merck	1	1	1.0	-
PHOTOTHERAPY AND PHOTOCHEMOTHERAPY				
PUVA, 'leg PUVA'	8	7	4.3	4.0
Sunbed, sunlamps, heat treatment	8	5	4.2	2.0
DITHRANOL				
Dithranol	4	4	4.5	-
Dithrocream (various percentages)	12	12	3.0	-
Psorin	1	1	4.0	-
TAR PREPARATIONS				
Alphosyl	5	5	2.6	-
Psoriderm cream	1	1	1.0	-
'Tar baths'	2	0	-	4.0
Tar + salicylic acid	1	1	5.0	-
Topical tar treatments	16	16	2.6	-
MISCELLANEOUS				
Acitretin	1	1	5.0	-
Arsenic	1	1	3.0	-
Methotrexate	1	1	5.0	-
Salicylic acid	4	4	2.3	-
Vitamin injections	1	1	5.0	-
UNKNOWN				
'Benelate'	1	1	2.0	-
'Cream with bandages'	1	0	-	3.0
'Hormone cream'	1	1	1.0	-
'Injections'	1	1	3.0	-
'Made up cream'	1	1	1.0	-
'Neodex'	1	1	4.0	-
'Novovate'	1	1	3.0	-
'Pill'	1	0	-	5.0
'Psorex'	2	2	3.5	-
'Sugary medicine'	1	1	1.0	-
'Tablet'	1	0	-	4.0

TABLE 4.10 Psoriasis treatments reported not to be available from medical sources

	No. of subjects who had heard of this treatment	*No. of subjects who had heard of this treatment and had also used it*	*Mean Rating if treatment used*	*Mean Rating if treatment not used*
PHOTOTHERAPY				
Hospital treatment (inc PUVA)	4	1	4.0	4.3
Sun lamps	5	4	1.8	4.0
Sun	6	6	4.5	-
TAR PREPARATIONS				
'Brown sticky bandage'	1	1	1.0	-
Coal Tar baths	1	0	-	3.0
Coal tar poultices	1	0	-	2.0
HERBAL				
Herbal soap	1	1	1.0	-
'Herbal treatment'	2	0	-	1.0
Potters No.143	1	1	1.0	-
Potters psoriasis ointment	1	1	4.0	-
TOPICAL PREPARATIONS				
Baby oil, witchhazel & glycerine	1	1	4.0	-
E45 cream	4	4	3.0	-
E45 bath oil	1	1	3.0	-
Hand cream	1	1	1.0	-
M & S Vegetable oil	1	1	5.0	-
Natural yogurt	2	2	1.0	-
Nivea cream	2	2	2.5	-
Olive oil	1	1	1.0	-
Ponds cocoa butter	1	1	2.0	-
Probase 3	1	1	5.0	-
'Psoreen'	1	1	1.0	-
'Psorigel'	1	1	1.0	-
Royal jelly & Bergamot cream	1	1	4.0	-
Savlon	1	1	1.0	-
Vaseline	2	2	3.0	-
Vaseline hand cream	1	1	4.0	-
Vaseline Demacare	2	2	1.0	-
Whiskey & Olive oil	1	1	3.0	-
Zam-buk	1	1	5.0	-
Zinc & Castor oil	1	1	1.0	-
ORAL MEDICATION				
Cod liver oil capsules	1	1	1.0	-
Evening Primrose capsules	3	3	2.3	-
Vitamin A	1	1	2.0	-
Vitamin B6	1	1	2.0	-
Yeast	1	1	1.0	-
BATH ADDITIVES				
Sea Salt	1	1	1.0	-
Sea Salt (Dead Sea)	1	0	-	3.0
MISCELLANEOUS				
Avoiding spicy food	1	1	5.0	-
Dead Sea clinic	6	6	-	2.8
'Doctor fish of Kangul'	3	3	-	1.7
Faith healer	1	0	-	1.0
Hypnotism	2	2	-	1.5
Lowering stress levels	1	1	2.0	-
Regular sea bathing	2	2	4.5	-

Question 30

The respondents were asked to rank seven possible sources of information about psoriasis (*doctors, newspapers, magazines, television, radio, family and friends,* and *other psoriasis sufferers*) in order of which had provided them with most information. The number of respondents and number ranking each source first are shown in Table 4.11.

Table 4.11 Ranking of sources of information about psoriasis.

Source	*No. of respondents who chose this option*	*No. ranking first*
Doctors	37 (100)	11 (29.7)
Magazines	34 (91.9)	9 (26.5)
Other psoriasis sufferers	35 (94.6)	6 (17.1)
Family and friends	34 (91.9)	5 (14.7)
Radio	32 (86.4)	3 (9.4)
Television	32 (86.5)	2 (6.3)
Newspapers	32 (86.5)	1 (3.1)

Question 32

Do you think it would help you to control your condition if you knew more about psoriasis?

Only one person said they did not know whether more knowledge about psoriasis would help control their condition, and 6 said it would not. This leaves (81%) who thought extra knowledge would definitely help to control the condition. Content analysis of the reasons given revealed eight distinct concepts, listed in Table 4.12.

Table 4.12 Content analysis of reasons why more knowledge would help control psoriasis.

To discover what treatments are available	13
A simple desire to know more	9
To discover and avoid substances or situations that might precipitate a relapse	4
Knowledge would help allay worry about the condition	4
To increase the motivation to persist with treatments	4
To be in a position to predict fluctuations in severity	2
To help cope with having psoriasis	2
To be able to give other people correct information	1

4.6 **Discussion**

The interviews lasted between 15 and 45 minutes per subject and gave a total of 263 pages of transcript. All named references to individuals in the text were removed and all tapes erased after transcription and checking. Combining the responses under the headings outlined in section 4.3.1, the main themes are summarised below, and where appropriate, comparisons made with the results of Lanigan & Farber's (1990) pilot study of psoriasis patients' knowledge, and Lanigan & Layton's (1991) survey.

4.6.1 **Etiology**

Neither Lanigan & Farber nor Lanigan & Layton explicitly inquired about beliefs concerning the etiology of psoriasis, but two questions in the present study did (Questions 4 and 6). Two important points arose from the responses to these questions. First, two thirds of respondents were aware that there is a hereditary aspect to psoriasis, and second, one third of respondents thought that specific groups of people tend to get psoriasis more than others. When probed about the reason why these groups get psoriasis more often, half the respondents indicated that it was because they were under a lot of stress or experiencing a lot of worry.

There is considerable evidence to suggest that psoriasis is hereditary. Over the past two decades theories about the exact nature of the genetic mechanisms have moved away from simple single gene dominant or recessive inheritance towards a multifactoral inheritance mechanism which suggests that several genes are required in a certain combination for psoriasis to be inherited (e.g. Watson *et al*, 1972, and especially Andressen & Henseler, 1982, quoted in Mier & van de Kerkhof). The subjects in the present study seemed quite aware of the hereditary aspects.

There is, however, less evidence concerning the link between stress and psoriasis, and no evidence at all that stress *causes* psoriasis. Some authors have suggested that stress can precipitate relapse or flare of psoriasis (e.g. Seville, 1977, 1978, 1989; Gaston *et al*, 1987) but others dispute this link (most notably Shuster, 1979). The main problem with research on stress and psoriasis is that almost all the studies have been retrospective: that is, patients have been asked to recall stressful life events over a period of months or years, and these events were then associated with psoriasis state (which was often also assessed retrospectively by the patient at the same time - e.g. Baughman & Sobel, 1971). Shuster (1979) argues that anamnestic studies of this sort cannot provide evidence for stress-psoriasis links simply because persistent questioning by the dermatologist leads patients to the belief that there *is* a link, and they begin to respond accordingly. Shuster argues further that continual reinforcement of this view from family mem-

bers and medial care professionals (and newspaper and magazine articles, it might be added) serves to bias any attempt to evaluate stress levels retrospectively. The prospective investigation by Gaston *et al* (1987) employed a more carefully designed methodology, but only measured psoriasis on the scalp and used only four subjects. While those authors found a significant correlation between stress (measured by the Life Experiences Survey) and psoriasis in their sample, they themselves note that their results cannot be generalised. No definite link has therefore been established between stress and psoriasis severity.

As far the the present research is concerned, regardless of whether or not stress actually does influence the course of psoriasis, the mere fact that considerable debate is in progress would be sufficient for patients to be aware of the possibility, since this debate is reflected not only in scientific journals but also in more popular publications accessible to a wider audience (e.g. Marks, 1981; and more particularly Gibbons, 1985, which contains a chapter entitled *"The Stress Factor: Learn to control your tension and your psoriasis will improve"*). While none of the respondents in the present study said they had read these specific publications, much has been written in popular magazines which reflect this view.

To summarise, two thirds of respondents knew that psoriasis can be hereditary and one third believed that some groups of people get psoriasis more often than others: especially those whose lifestyles involve stress or worry.

4.6.2 **Pathophysiology**

In common with those who suffer from other medical conditions (e.g. Rheumatoid Arthritis - Hill *et al,* 1991) respondents in the present study appeared to be quite poorly informed about the actual nature of their condition. While two thirds did think that they knew what happens to the skin in psoriasis, the remainder said they had no idea at all (Question 18). Of those that did think they knew, 21% gave an explanation which was not correct. This figure corresponds to 70% of Lanigan & Farber's sample who answered the negatively worded question that skin cells multiply too *slowly* in psoriasis and 63% who correctly answered the same question in Lanigan and Layton's sample.

A further question related to pathophysiology both in this study and in Lanigan's questionnaire and concerned the Koebner phenomenon. It is interesting that over half the respondents in the present study thought that psoriasis could not develop at the site of damaged skin and 41% thought it could. Two thirds of both Lanigan & Farber's American sample and Lanigan & Layton's UK sample were aware of this phenomenon, while

only 8% and 10% respectively thought it could not happen. An important factor in managing psoriasis is identification of patients who exhibit Koebner responses. It is disturbing to note that 52% thought that skin trauma cannot lead to the formation of psoriasis lesions. This may be due to personal experience, that is, those who had not experienced Koebner reactions have no reason to suspect that they may occur, but it may also be that no causal link had been drawn between skin trauma and psoriasis.

It has been shown that educating patients about their illness can result in significant increases in treatment compliance (e.g. Raven, 1988) and may result in a more encouraging prognosis (e.g. Kendall *et al*, 1979). This lack of basic knowledge is therefore cause for concern among health professionals and some steps are being taken to remedy it (Reynolds, 1978; Caplan, 1973). This is particularly important where individuals may be worried about psoriasis leading onto other diseases. Twenty two percent of respondents in the present study thought that psoriasis was an early form of some other condition (mostly arthritis, but skin cancer was also mentioned), and this may reflect a misunderstanding. For example, one possible side-effect of prolonged PUVA treatment can be skin cancer, yet psoriasis *per se* is not statistically associated with increased levels of cancer (Lindelof, 1991). Another factor may be that anti-cancer drugs (e.g. methotrexate) are sometimes used to treat psoriasis, which could lead people to link the two conditions. It is also possible that knowledge of the existence of psoriatic arthropathy may have led some respondents to believe it to be a progressive process from skin pathology to joint problems.

To summarise, respondents in the present study were quite poorly informed about the physical nature of their condition and about half were unaware that skin trauma can lead to psoriasis. The idea of psoriasis being an early form of another condition was present, most often relating to cancer or arthritis.

4.6.3 **Course of psoriasis**

In common with Lanigan's samples, the current sample did not generally think that psoriasis is infectious or spread by autoinfection (Question 10), although one woman did explain the Koebner phenomenon in terms of open wounds "letting germs in". Some evidence of deeper knowledge of the physiological mechanisms which influence the course of psoriasis came from subjects' explanations of why they thought pregnancy could affect psoriasis (Question 14). 'Hormonal changes' was the most frequently cited explanation, which suggests that some patients may be aware that some authors have found peaks of age at onset around puberty and the climacteric (e.g. Gunawardena *et al*, 1978; Holgate, 1975), i.e. at times of hormonal changes.

It is interesting to note that 95% of respondents thought that psoriasis would never clear and stay cleared permanently. This belief may be a reflection of the fact that there is no *cure* for psoriasis. Over 80% of subjects in both Lanigan's samples thought that there was no cure for psoriasis and the majority of the remainder were unsure, rather than suggesting that there is cure. Thus, even though the data presented by Farber & Nall (1974) concerning remissions indicate that extremely long periods clear from psoriasis are possible, the vast majority of sufferers do not believe this will happen to them.

One final question in the present study has bearing on this explanatory model category: that is, whether subjects believed acquiring more knowledge about psoriasis would help them control their condition (Question 32). Over 80% of subjects said they thought more knowledge would help them, and the two most common reasons given were to discover what new treatments were available and simply a desire to know more about the condition. Interestingly, Ramsay & O'Reagan (1988) reported that 86% of their sample of 104 psoriasis patients thought they would be able to cope better with their condition if the general public were more knowledgeable about psoriasis, suggesting that the general public have relatively little knowledge about the condition. Indeed, Lanigan & Farber's study compared responses of psoriasis sufferers to those of the general public and Lanigan & Layton concluded that these responses "demonstrated such a low level of knowledge about the condition that it provided no useful information". In Jowett & Ryan's (1985) study of dermatology patients' feelings about medical care, only 50% said they were satisfied with the information they had been given.

To summarise, respondents in general did not think their psoriasis would ever clear and not return, even though evidence suggests that this is possible, but they did show some knowledge of possible hormonal involvement in the course of psoriasis. The majority thought more knowledge of psoriasis would help them control their condition.

4.6.4 **Treatment**

Thirteen and a half percent of Lanigan & Farber's sample and only 6.5% of Lanigan & Layton's sample of UK psoriasis sufferers thought that specific diets could affect psoriasis. In contrast to these findings, 40% of the current sample thought that particular foods or specific diets could help psoriasis, although no information was collected on whether the respondents had actually tried any particular diet. Jensen (1990) reported 11.6% of 491 psoriasis outpatients (postal questionnaire) using diet change as 'alternative' therapy for psoriasis compared with 18.2% of 424 patients suffering from atopic dermatitis. The discrepancy between these findings can be explained by the wording of the question. Jensen was interested in whether patients had or were currently using diet change

as therapy, while the present study inquired whether subjects thought diet manipulation *might* help psoriasis. In contrast to this, Lanigan & Farber's questionnaire required a response to the item "Specific diets may *clear* psoriasis" while Lanigan & Layton changed the wording of this item to "Specific diets may *cure* psoriasis" (my emphases). Given that 87% of their sample agreed that there is no cure for psoriasis and a further 8% were unsure, it is hardly surprising that such a small number thought diets would "cure" psoriasis.

It had been noted in the previous study that subjects often remarked that they had tried a large number of treatments for their psoriasis, and this was examined further in the present study. There are a very large number of medical treatments available for psoriasis based on a range of basic pharmaceutical agents: the group as a whole mentioned 32 specific treatments by name and described a further 11 whose name they could not remember. However, individual respondents named only a median of three treatments that they had heard of, and said they had used only a median of three.

Respondents estimated the effectiveness of treatments they had never used higher than treatments they had used. This reinforces the impression that psoriasis sufferers are keen to try almost any treatment and retain some hope that they may find one that works better than those they have already tried. This is also reinforced by the apparent willingness to try "alternative" medicines. The respondents in the present study could name a median of two alternative treatments and had used a median of one, but the lower ratings for effectiveness of these treatments suggests that they are not particularly effective. Jensen (1990) found that 42.5% of his sample of 506 psoriasis patients had used, or were currently using 'alternative' treatments, which compares to 62% of respondents in the present study admitting that they had used alternative treatments at some point in the course of the disease. However, this figure should be interpreted with care since some of the 'alternative' treatments named in the present study were in fact standard medical treatments (e.g. PUVA, coal-tar baths). Wadswoth, Butterfield & Blaney (1971) have suggested that about 75% of illness episodes are treated by non-medical practitioners or by self-medication, and the data from the present sample supports this. The motivation to seek non-medical therapy may be related to the general dissatisfaction with medical treatment noted in the previous study and examined in more detail by Jowett & Ryan (1985), who found that only 19% of a sample of 100 dermatology patients (including psoriasis patients) expressed positive opinions about their GPs.

To summarise, subjects do tend to use "alternative" treatments, including diet change, but report that medical treatment is more effective than non-medical treatment, even though the majority think that all medical treatments are based on the same fundamental agents.

4.6.5 **General psoriasis knowledge**

Some of the data collected in the present and previous studies does not fit easily into any of Kleinman's explanatory model categories. It does, nevertheless provide useful insights into lay perceptions of psoriasis.

Epidemiology

Informal discussions with patients had suggested that their estimates of the prevalence of psoriasis would be high, and 92% of subjects made some estimate of the prevalence of psoriasis by choosing an option from a card. Lanigan & Farber had suggested that some of their respondents may have estimated incorrectly because of a fundamental misunderstanding of the concept of percentages, so the options of the card for the present study were phrased as:

Don't know
Less than 1 in 100
About 2 in 100
About 5 in 100
About 10 in 100
About 15 in 100
About 20 in 100
More than 20 in 100

The modal response was in the 5% category, which may be due to patients being aware of hospital or clinic presentation rates rather than true prevalence. However, the analysis of response phraseology would tend to suggest that individuals were simply guessing and were not in fact aware of any figures. Given that these guesses tended to be over- rather than under-estimates, it is possible that they were based on the number of people that sufferers had come into contact with at dermatology clinics: particularly those subjects who had received in-patient or PUVA treatment in the past. Forty six percent of Lanigan and Farber's American sample estimated disease prevalence to be between 1 and 7%, but the remainder were quite widely inaccurate, ranging from 0.001% to 75%. Lanigan & Layton found an even wider range of estimates (1-99%), which supports their explanation about fundamental misunderstandings of percentages. The estimates obtained in the present study were anchored to a minimum of <1% and a maximum of >20% and the responses were forced choice rather than free estimates, which explains why there is somewhat less variation in the present study than in Lanigan & Farber's. Those authors did not report the precise wording of their question, so it

is impossible to ascertain whether respondents were instructed to guess if they did not know the answer.

Lanigan & Farber found 66% of their sample reporting that men and women suffer in equal numbers, and this compares with 68% in the present study. It is interesting to note that the reasons given for any inequality in the present study were based either on personal knowledge of other sufferers, or on the assumption that worry or stress causes psoriasis and one sex is affected by these factors more than the other. Savin (1970) found that half of his patients related psoriasis to worry, and this appears to be a commonly held belief.

To summarise, psoriasis sufferers tend to overestimate the prevalence of psoriasis, think that men and women suffer to the same degree, and are generally quite well aware of the hereditary nature of the condition.

4.6.6 **Sources of information**

Most of the respondents reported that they had received information about psoriasis from all the sources listed. About one third ranked the doctor (which included both GP and hospital dermatologist) as their best source of information, which compares with 72% of Lanigan and Layton's sample and 90% of Lanigan & Farber's sample. This supports the findings of Elliot-Binns (1973, 1986) who reported 95% of GP patients obtaining information about their condition from a variety of sources, and Frankel (1991) who specifically cited television, magazines and other media sources as valuable information-providing resources for the lay public.

4.7 **Conclusions**

This study has examined patients knowledge and beliefs about psoriasis through the vehicle of a semi-structured interview. Levels of knowledge are broadly comparable to those found by Lanigan & Layton (1991), but less comparable to those found by Lanigan & Farber (1990). This may be due to the fact that the latter used an American sample while subjects in the former were British.

The findings are of interest on two levels. First they provide valuable information about the levels of knowledge that psoriasis sufferers have about their condition and, because the methodology allowed respondents to voice their own opinions instead of simply choosing options, give a broader picture of how sufferers perceive their condition than has been obtained by more restrictive methodologies. The beliefs that sufferers have about their condition influence the way they respond to it psychologically, and the way

they treat it physically, and investigations of the effects of psoriasis all too often fail to take this into account. Second, the results of this study should be of interest to medical practitioners who treat psoriasis sufferers. There is clear evidence that some important aspects of the condition are not understood by the sufferers and the results of this study can be used to guide information-providing strategies in future. Beliefs about medical conditions are influenced by the knowledge patients have about the condition, and studies such as this one which evaluate that knowledge help clarify issues of importance to sufferers.

Chapter Five

Prospective Investigation of Psychological Variables in Psoriasis Outpatients

5.1 **Introduction**

The results of the first study reported in Chapter 3, showed that psoriasis sufferers are more anxious, have more cognitive and somatic anxiety symptoms, are more depressed, differ in levels of self-esteem, have more trouble sleeping and more pain than controls. This may indicate that psoriasis sufferers in general have higher levels of these variables regardless of the state of their psoriasis, but it may also be the case that levels of these variables are dependent on how much of the body is affected by psoriasis. This question could not be answered with the data obtained in Chapter 1 because the psoriasis was very mild. The aims of the present study are first to ascertain whether these variables fluctuate within individuals as the severity of psoriasis alters and second, to examine in more detail the nature of sleep and pain problems associated with psoriasis.

5.2 **Questionnaires**

The results of the first study showed levels of depression in psoriasis sufferers to be significantly higher than in non-sufferers, but not generally high enough for classification as a clinical "case". Snaith (1987) has argued that the most appropriate measures of depression concentrate on anhedonic symptoms, such as loss of pleasure in everyday activities, and avoid symptoms which may coincide with those occurring in somatic illness, such as insomnia or excessive weight variation. This argument is particularly relevant when people who are physically ill are under investigation, as is the case in the present study.

With this in mind, Zigmond & Snaith (1983) have developed the Hospital Anxiety and Depression Scale (HADS) to assess levels of depression and anxiety in physically ill populations. The initial validation used 100 hospital outpatients aged between 16 and 65 and presenting with a variety of conditions, and the results suggested that scores on the HADS identify possible or probable "cases" if appropriate cutoff points are chosen. The range of scores is 0 to 21 for both anxiety and depression (derived from seven questions in each category), and Zigmond & Snaith suggest a cutoff point of ≥8 for a borderline or possible "case" and ≥11 for a probable "case", as assessed by clinical interview. Perhaps of more importance for the present study, the authors also demonstrated that the HADS can be used to measure *levels* of depression and anxiety which they showed correlated with clinical assessments of severity, rather than simply to classify people as depressed or not depressed, anxious or not anxious. By comparing scores on the HADS in a physically ill group with scores from a sample matched for age and sex who were not physically ill, Zigmond and Snaith were able to demonstrate that scores were not contaminated by the presence of physical illness. Finally, since depression and anxiety tend to co-exist, it is important that any measuring instrument success-

fully distinguishes the two. Zigmond & Snaith found no significant correlation between anxiety scores and scores for depression on the HADS in a subsample of patients who exhibited only one of the conditions, as diagnosed by clinical interview.

Wilkinson & Barczak (1988) have subsequently validated the HADS using ROC analysis in a sample of 100 general practice patients, and found a specificity (that is 1 – the false positive rate) of 0.86 which is comparable to that found for the GHQ in the same population (0.85), and a sensitivity (that is, the true positive rate) of 0.90 compared with 0.77 for the GHQ. They also noted that the HADS was easier for subjects to complete. Because of its ability to measure pre-clinical levels of both depression and anxiety as well as identifying cases, coupled with the impressive validity data and acceptability to patients, the HADS was used in the present study.

The results of the previous study showed psoriasis sufferers had significantly more anxiety symptoms than controls on the Cognitive Somatic Anxiety Questionnaire (CSAQ). Validity data for that instrument has already been presented (Chapter 3), and the same questionnaire was used in the present study to further examine the relationship between anxiety symptom type and psoriasis severity. Self-esteem was assessed with the Self-Esteem Questionnaire (Robson, 1989) used in the previous study: validity data have already been presented for that instrument (Chapter 3).

The measurement of sleep quality is problematic because the *quality* of sleep is necessarily subjective. While it is quite possible to measure some of the more observable aspects of sleep: sleep latency, sleep duration, number of awakenings, for example, as well as more serious symptoms of sleep pathology, these only form part of sleep quality. However, there is evidence that these aspects of sleep quality measured by self-report questionnaires not only correlate quite well with objective measurement (e.g. Lewis, 1969) but also with health status (e.g. Belloc & Breslow, 1972; Frederick, Frederichs & Clark, 1988). There are several self-report sleep questionnaires available but many have not been properly validated, or were designed to assess sleep patterns in specific populations. There are, however, two well validated general self-report questionnaires available. For the purposes of the present research, the Rehabilitation Research Centre Sleep Habit Questionnaire devised by Hyyppä & Kronholm (1987) was rejected because, although its statistical properties are acceptable, the translation into the English language version is quite crude. The questionnaire chosen was the Pittsburgh Sleep Quality Index (PSQI) developed by Buysse and his team at the University of Pittsburgh (Buysse *et al*, 1989). The questionnaire elicits information about sleep habits over the preceding month. This timescale was used to discriminate persistent

from transient sleep problems. As well as a global sleep quality score in the range 0-21 (higher scores corresponding to poorer sleep quality), the instrument provides seven subscales that examine *sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medication,* and *daytime dysfunction.* These subscales in turn correspond to areas examined in clinical interviews for sleep problems. Validation studies of the PSQI in populations of "good" and "poor" sleepers, depressives, and individuals suffering from disorders of initiating and maintaining sleep and disorders of excessive somnolence revealed a Cronbach's α of 0.83, indicating good internal consistency, and test-retest correlation was 0.85 on the global sleep quality score, and between 0.65 and 0.84 on the subscale scores. The questionnaire revealed different patterns of scores for each of the groups studied, both for the subscales and for the global sleep quality score, and thus discriminates "good" and "poor" sleepers, as well as depressed patients and patients with diagnosed sleep disorders. The PSQI was therefore used in the present study.

Melzack & Wall (1982) have demonstrated that the measurement of pain is not simply a matter of measuring pain intensity. Rather, they suggest that the quality of pain is of as much importance as its intensity. Indeed Melzack (1975) wrote:

> To describe pain solely in terms of intensity is like specifying the visual world only in terms of light flux without regard to pattern, colour, texture, and the many other dimensions of visual experience. (p.278).

In an attempt to provide a reliable means for assessing pain quality, Melzack (1975) developed the McGill Pain Questionnaire (MPQ) based on work by Melzack & Torgerson (1971) which identified and categorised lists of verbal descriptors of the pain experience. This instrument gives information on the quality of pain in three main areas: *sensory*, which contains words to describe how the pain feels, *affective*, which contains words to describe how the pain is interpreted, and *evaluative*, which offers an overall judgment of the pain. There is a further category labelled *miscellaneous* which includes other pain descriptor words not classified in the above categories (although Chapman *et al*, 1985, have noted that these seem to be mostly sensory descriptors), and finally a scale labelled *present pain intensity* which gives a rating of how bad the pain is. Melzack's (1975) original study involved rating of the pain descriptor words so that a scale was devised which represents equally spaced ratings. Because of its ability to describe the quality of the pain experience, the MPQ was used in the present study.

5.3 **Subjects**

Part of the problem with the previous study was the generally low level of psoriasis, so a group of sufferers whose disease was more severe was required for the present study. PUVA therapy (oral doses of 8-methoxypsorlen followed by controlled ultra-violet type A exposure) is a relatively expensive, though effective, treatment for psoriasis, and as such is usually reserved for those cases where psoriasis does not respond to topical or systemic treatment, where these are contraindicated, or where the condition is particularly severe. Thus, in order to obtain a sample whose condition was severe, patients undergoing PUVA therapy were taken as the sampling frame for the present study. Over a three month period, all patients currently undergoing PUVA therapy at Chester-le-Street General Hospital were approached by the nursing staff and asked to participate. A brief outline of the study was given in writing to the patients and written consent was obtained at that time. A total of 35 patients agreed to take part; 54% were females and 46% males. The mean age was 46 yrs (SD 17.8, range 15–74) and the mean time since onset of psoriasis was 23.3 years (14.4, 1–58).

5.4 **Procedure**

Ethical permission was obtained from the North Durham Health Authority Ethics committee for this study (ref EC275/90).

One subject did not provide a telephone number so she was contacted by letter, but the remainder were contacted by telephone and a time arranged for them to be visited in their own homes. They were each asked to complete the five questionnaires, and a record was made of the extent of their psoriasis using SKINMAP. Visits lasted between 20mins and 1 hour. Subjects were told that the study would involve being seen on two occasions, and a further visit was organised twelve weeks later, when the same questionnaires were completed and a further record of disease severity made.

Subjects were informed that the study was concerned with how they felt about their psoriasis and the general nature of the questionnaires was explained to them. They were also asked whether they would mind having their psoriasis recorded on computer. None refused: indeed, many expressed interest at what was to them a novel way of recording their disease. A record was made of their condition, then they were asked to complete the questionnaires. Subjects were not told the precise nature of the variables each questionnaire examined, but for each questionnaire the instructions were read aloud to the subject and they were asked whether they understood the instructions. Any questions were answered as fully as possible. There were no objections or difficulties, other than considerable deliberation in some cases about the answer which best described how they felt.

Minimal debriefing was given at the end of the first session. Those subjects who pressed for explanation were asked whether they would mind waiting until after the second session for a full debriefing. Some subjects asked to see the mapping made of their condition, but again they were asked to wait until the end of the second session. All appeared to accept this. At the end of the second session the subjects were told that the study was concerned with examining levels of depression, anxiety, self-esteem, and associations between psoriasis and physical problems such as sleep disturbance and pain. It was stressed that examining these variables in no way implied that the subject *was* depressed or anxious. If subjects asked to see the SKINMAP record they were shown it. Any questions were answered fully. The subjects were urged to consult medical advice for answers to questions about treatment, problems controlling psoriasis, etc.

5.5 **Analyses**

In the analyses that follow, sex was coded 0 for males and 1 for females. For those variables where parametric analysis was appropriate, regression analyses were used using GLIM 3.77. All variables that were not statistically significant were removed unless their removal affected the logic of the model. Where a difference between sexes was apparent in the slopes of the regression lines, the difference between intercepts for sexes was retained in the model regardless of whether or not it's coefficient was significantly different from zero. Otherwise, the variable 'sex' was only retained if its coefficient was significantly different from zero. Age at onset of psoriasis was not statistically significant in any of the analyses. For the sake of clarity, the intermediate steps of the analyses are not reported. The results of the analyses are presented in section 5.6, their meaning and implications are interpretted in section 5.7.

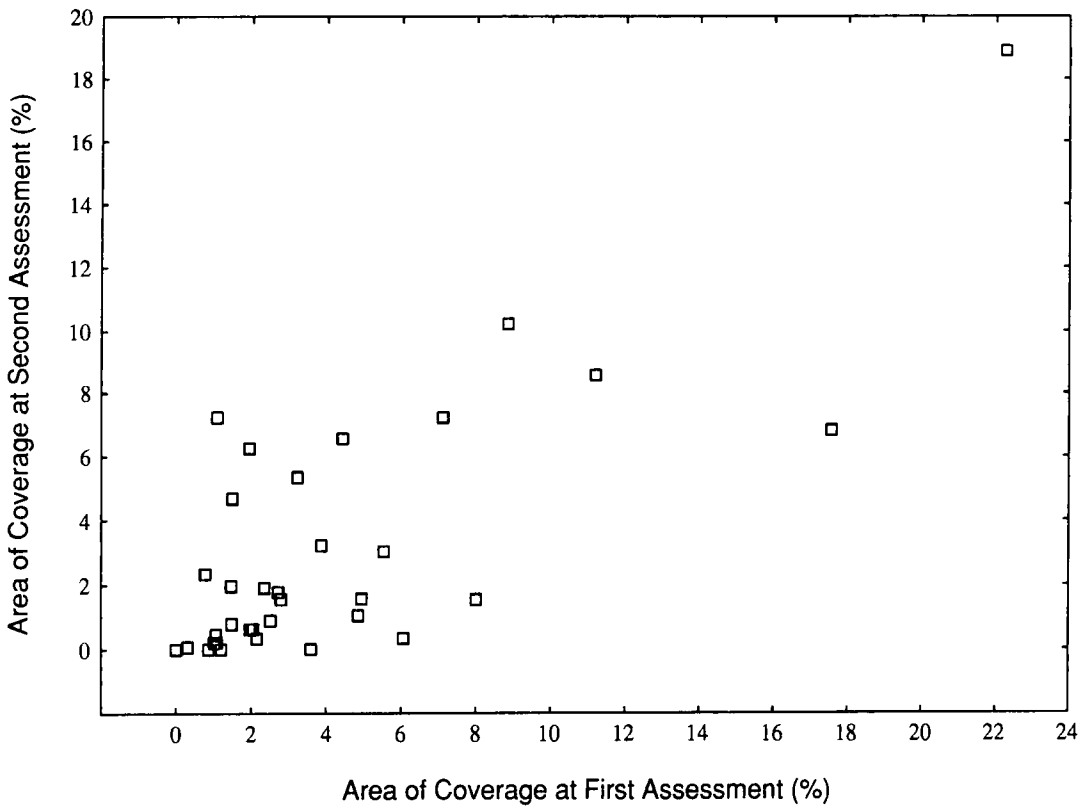
5.6 **Results.**

All except one of the subjects completed both sets of questionnaires with no missing data since the data were checked at the time of the visit and any omissions rectified. Unfortunately one subject died between the first and second assessment, so for the analyses below, figures quoted for the first assessment are based on 35 subjects and for the second on 34. Comparisons between assessments are based on the 34 subjects who completed both sets of questionnaires.

The mean area of coverage was 4.2% (SD 4.7, range 0 to 22.3%) on the first assessment and 3.1% (4.0, 0 to 18.9%) on the second. It can be seen therefore that the distributions are positively skewed and the means and standard deviations are given only for comparison with other studies. The median area of coverage at the first assessment was 2.51% (semi-interquartile range 1.85) and at the second was 1.55% (2.62). The areas of

coverage measured on both occasions are plotted in Figure 5.1, where it can be seen that for some subjects the disease improved, for some it worsened, and for some there was relatively no change.

Figure 5.1 Area of coverage of psoriasis estimated by SKINMAP on two occasions



5.6.1 **Depression**

Taken individually, the scores for the depression scale of the HADS would suggest that on neither occasion was the group a 'depressed' group. Set against a suggested cutoff point of ≥8, the mean score on the first assessment was 3.3 (SD 2.5, range 0 to 10) and on the second assessment 3.5 (3.1, 0 to 11). The mean *change* in depression scores was 0.2 (3.1, −8 to +10). The scores at the second assessment are particularly skewed. The median at the first assessment was 2 (SIR 1.5) and at the second was 2.5 (2.5). Three subjects scored above 7 at the first assessment, indicating possible depression, while five scored above 7 at the second assessment.

From the regression analysis summarised in Table 5.1, depression scores at the second assessment (time 2) were predicted by area of coverage, by change in area of coverage between the first and second assessments, and by time since onset of psoriasis, once the starting levels of depression had been taken into account. There was a significant difference between males and females in the coefficient for change in area of coverage and area of coverage at the second assessment. The value for R^2 was 0.67.

The Filliben correlation coefficient (Filliben, 1974), which is a measure of the normality of residuals, was 0.99. On 26 degrees of freedom, a value for this correlation coefficient above 0.9590 indicates an acceptable approximation to a normal distribution.

Table 5.1 Summary of estimates and analysis of variance for the regression of HADS depression at time 2 on five predictor variables.

Parameter	*Estimate*	*SE*	*t*	*Sig p<*
(Constant)	−0.55	0.95	−0.58	-
Sex (males=0, females=1)	−0.39	1.04	−0.38	-
Depression at time 1	0.52	0.15	3.46	0.01
Area of coverage at time 2	−0.065	0.12	−0.54	-
Area of coverage at time 2 × Sex	0.48	0.22	2.18	0.05
Change in area of coverage	0.86	0.20	4.40	0.001
Change in area of coverage × Sex	−0.76	0.24	−3.12	0.01
Time since onset (years)	0.10	0.028	3.63	0.01

Analysis of Variance

Source	*df*	*SS*	*MS*	*F*	*Sig p<*
Regression	7	215.3	30.76	7.47	0.001
Residual	26	107.2	4.12		
Total	33	322.5			

Chronological age is not significantly asociated with depression scores at time 2.

5.6.2 **Anxiety**

The scores for anxiety on the HADS on both occasions were moderately high. On the first assessment the mean was 7.6 (SD 4.0, range 0 to 19) and on the second the mean was 7.1 (4.1, 0 to 18). The mean change in scores was –0.5 (2.8, –6 to +7). Twelve subjects scored above 7 at the first assessment and the second assessment, while 7 scored above 10 at the first assessment compared with 6 at the second.

The regression model for anxiety scores at time 2 was somewhat less complex than for depression because there were no significant differences between sexes. Once the initial level of anxiety had been taken into account, the best predictors of anxiety at time 2 were area of coverage, change in area of coverage since time 1, and time since onset of psoriasis. This model fits the data well as evidenced by an R^2 value of 0.75 and a Filliben correlation coefficient of 0.99 for the residuals. The regression parameter estimates are summarised in Table 5.2 with an analysis of variance.

Table 5.2 Summary of estimates and analysis of variance for regression of HADS Anxiety scores at time 2 on four predictor variables.

Parameter	*Estimate*	*SE*	*t*	*Sig p<*
(Constant)	–1.31	1.17	–1.12	-
Anxiety at time 1	0.88	0.097	8.64	0.001
Area of coverage at time 2	0.21	0.098	2.14	0.05
Change in area of coverage	0.53	0.15	3.52	0.01
Time since onset	0.076	0.027	2.88	0.01

Analysis of Variance

Source	*df*	*SS*	*MS*	*F*	*Sig p<*
Regression	4	404.61	101.15	21.43	0.0001
Residual	29	136.92	4.72		
Total	33	541.53			

As with the depression scores, chronological age is not significantly associated with anxiety at time 2.

As far as cognitive and somatic components of the anxiety reaction are concerned, the scores on the CSAQ were similar at both assessments. The mean score at the first assessment on the Cognitive subscale was 15.6 (6.4, 7 to 29) and on the second assess-

ment was 16.1 (8.1, 7 to 35). This compared with 14.7 (4.8, 9 to 23) on the Somatic subscale at the first assessment and 14.6 (5.9, 7 to 27) at the second. The mean changes in scores were 0.26 (4.9, –8 to +12) on the Cognitive scale and –0.12 (4.2, –13 to +8) on the Somatic. Neither CSAQ scores nor the *ratio* of CSAQ scores at time 2 are significantly related to any independent variable except levels at time 1. The ratio of cognitive to somatic symptoms was 1.08.

5.6.3 Self Esteem

The SEQ gives a total self-esteem score and five subscale scores: *contentment, worthiness and personal significance; competence, resilience and control; attractiveness; value of existence;* and *self evaluation.* The range of scores for each subscale is 0–7.

Total SEQ

The mean total score at the first assessment was 142.7 (20.7, 106 to 200) and at the second was 146.8 (24.1, 97 to 191). This produced a mean change of 4.0 (18.0, –57 to +50). Once the initial total SEQ score had been taken into account, total SEQ at time 2 was significantly predicted by change in area of coverage, but there was a significant difference between males and females (Table 5.3). The value for R^2 was 0.71 and the Filliben correlation coefficient was 0.99, both of which indicate that the model fits the data well. Neither chronological age nor time since onset of psoriasis were significantly associated with total SEQ.

Table 5.3 Summary of estimates and analysis of variance for regression of Total SEQ scores at time 2 on four predictor variables.

Parameter	*Estimate*	*SE*	*t*	*Sig p<*
(Constant)	28.54	19.29	1.48	-
Sex (males=0, females=1)	–3.59	5.50	–0.65	-
Total SEQ at time 1	0.85	0.13	6.72	0.001
Area of Coverage at time 2	–0.93	0.63	–1.48	-
Change in area of coverage	–5.90	1.37	–4.33	0.001
Change in area of coverage × Sex	4.90	1.70	2.89	0.01

Analysis of Variance

Source	*df*	*SS*	*MS*	*F*	*Sig p<*
Regression	5	13649.5	2729.9	13.76	0.001
Residual	28	5554.5	198.4		
Total	33	19204.0			

Contentment, worthiness and personal significance

The mean scores for this subscale were 3.9 (1.2, 1.6 to 6.4) at the first assessment and 4.3 (1.2, 1.4 to 6.7) at the second. The mean change in scores was 0.4 (1.1, −3.6 to +2.9). None of the variance in this scale can be accounted or by any of the independent variables except the score at time 1.

Competence, resilience and control.

The mean scores for this subscale were 5.4 (0.8, 4.0 to 7.0) at the first assessment and 5.5 (0.8, 3.8 to 7.0) at the second. The mean change in scores was 0.07 (0.7, −12.1 to +1.5). Once the initial scores had been accounted for, absolute area of coverage, change in area of coverage and sex were found to be significant predictors (Table 5.4). With an R^2 of 0.72 and a Filliben correlation coefficient of 0.99, the model can be seen to fit the data very well.

Table 5.4 Summary of estimates and analysis of variance for regression of Competence, Resilience and Control SEQ scores at time 2 on four predictor variables.

Parameter	*Estimate*	*SE*	*t*	*Sig p<*
(Constant)	1.40	0.61	2.28	0.05
Sex (males=0, females=1)	−0.079	0.24	−0.33	-
Competence etc. scores at time 1	0.78	0.11	6.87	0.001
Area of coverage at time 2	0.0072	0.027	0.26	-
Area of coverage at time 2 × Sex	−0.13	0.046	−2.77	0.02
Change in area of coverage	−0.16	0.047	−3.28	0.01
Change in area of coverage × Sex	0.15	0.059	2.45	0.02

Analysis of Variance

Source	*df*	*SS*	*MS*	*F*	*Sig p<*
Regression	6	16.80	2.80	11.52	0.001
Residual	27	6.56	0.24		
Total	33	23.36			

Attractiveness

The mean score for this subscale at the first assessment was 5.2 (0.9, 3.4 to 7.0) and at the second 5.3 (0.9, 3.6 to 7.0). The mean change between assessments was 0.01 (0.9, −2.2 to 2.4).

The the regression model fitted the data somewhat less well with an R^2 value of 0.48 and a Filliben correlation coefficient of 0.98. Time since onset was not a significant predictor, but there was a significant difference between sexes for the effect of change in area of coverage, the only statistically significant independent variable once starting levels at time 1 had been entered into the model (Table 5.5). Chronological age is not significantly associated with attractiveness scores.

Table 5.5 Summary of estimates and analysis of variance for regression of Attractiveness SEQ scores at time 2 on four predictor variables.

Parameter	*Estimate*	*SE*	*t*	*Sig p<*
(Constant)	2.29	0.72	3.20	0.01
Sex (males=0, females=1)	0.021	0.25	0.083	-
Attractiveness scores at time 1	0.58	0.14	4.24	0.001
Area of coverage at time 2	–0.049	0.033	–1.49	-
Change in area of coverage	–0.22	0.066	–3.25	0.01
Change in area of coverage × Sex	0.21	0.083	2.51	0.02

Analysis of Variance

Source	*df*	*SS*	*MS*	*F*	*Sig p<*
Regression	5	12.00	2.40	5.12	0.01
Residual	28	13.13	0.47		
Total	33	25.13			

Value of existence

The mean score on this subscale at the first assessment was 5.01 (1.0, 3.2 to 7.0) and at the second 4.97 (1.4, 1.2 to 7.0). The mean change was –0.04 (1.2, –4.5 to +1.8). There are no sex differences in this model (Table 5.6) which is somewhat simpler than the others on the self-esteem questionnaire. Only change in area of coverage and time since onset are statistically significant once starting scores have been taken into account. The value for R^2 was 0.58, which suggests a fairly parsimonious model, and the Filliben correlation coefficient of 0.98 indicates that the residuals are quite normally distributed. Chronological age is not significantly associated with this subscale.

Table 5.6 Summary of estimates and analysis of variance for regression of Value of Existence SEQ scores at time 2 on four predictor variables.

Parameter	*Estimate*	*SE*	*t*	*Sig p<*
(Constant)	0.85	0.84	1.00	-
Subscale score at time 1	0.96	0.17	5.70	0.001
Area of coverage at time 2	−0.0069	0.042	−0.17	-
Change in area of coverage	−0.18	0.055	−3.21	0.01
Time since onset (years)	−0.037	0.012	−3.02	0.01

Analysis of Variance

Source	*df*	*SS*	*MS*	*F*	*Sig p<*
Regression	4	36.33	9.08	10.02	0.001
Residual	29	26.28	0.91		
Total	33	62.61			

Self evaluation

The mean score at the first assessment was 4.9 (1.6, 0.5 to 7.0) and at the second 5.1 (1.5, 0.0 to 7.0) which gives a mean change in self-evaluation scores of 0.09 (1.56, −3.5 to +5.5). None of the variance in this subscale could be accounted for by any of the independent variables and there were no differences between males and females.

5.6.4 **Sleep quality**

The PSQI returns a global sleep quality score and seven subscales. None of the subscales showed any relationship with psoriasis-specific variables.

Total Sleep Quality Scores.

The mean total sleep quality score at the first assessment was 5.71 (4.0, 0 to 15) and at the second assessment was 5.68 (4.1, 0 to 16). This results in a mean change over assessments of 0.12 (2.6, −7 to +6). These data are moderately skewed. The median value at the first assessment was 5.0 (3.0) and at the second was 4.5 (2.5).

The regression model summarised in Table 5.7 is quite complex. Once the starting levels have been taken into account, scores on this scale are predicted by change in area of coverage and the time since onset of psoriasis, but there is an interaction with sex on this variable. The analysis produces an R^2 of 0.76, which is high, and the Filliben correlation coefficient was 0.99 which confirms that the residuals are approximately normally distributed.

Table 5.7 Summary of estimates and analysis of variance for regression of Total Sleep Quality scores at time 2 on five predictor variables.

Parameter	*Estimate*	*SE*	*t*	*Sig p<*
(Constant)	−2.42	1.21	−2.00	-
Sex (males=0, females=1)	4.04	1.54	2.62	0.02
Global PSQI score at time 1	0.85	0.10	8.23	0.001
Area of coverage at time 2	0.078	0.12	0.68	-
Change in area of coverage	0.24	0.13	1.88	-
Time since onset	0.12	0.045	2.70	0.02
Time since onset × Sex	−0.13	0.062	−2.05	0.05

Analysis of Variance

Source	*df*	*SS*	*MS*	*F*	*Sig p<*
Regression	6	418.33	69.72	14.59	0.001
Residual	27	129.11	4.78		
Total	33	547.44			

5.6.5 **Pain**

The MPQ returns one scale for the rating of pain intensity (Present Pain Intensity - PPI) and five scales comprising pain descriptors (Pain Rating Index - PRI - scales of *sensory, affective, evaluative, miscellaneous,* and *total*). The respondents were instructed to assess the pain they may be experiencing from psoriasis, not from any other illness they might have. Only the total PRI scale is suitable for regression analysis. The remaining four pain rating subscales and the Present Pain Index are therefore analysed by chi-square. The purpose of this study was to ascertain whether change in severity of the condition was related to change in the dependent variables. The subscale data were therefore organised as 2 × 3 contingency tables and analysed by chi-square. The two columns of the contingency tables correspond to *1)* improvement of psoriasis between time 1 and time 2, *2)* worsening of psoriasis over that period. The rows of the contingency tables correspond to subscale scores which *1)* improved over assessments, *2)* which did not change, and *3)* which worsened between assessments. The null hypothesis in each case was that the distribution of proportions in each cell are due to chance. It can be seen that some of the expected frequencies in the contingency tables are rather small. Debate about whether small expected frequencies should preclude the use of the chi-square test has effectively been resolved by Bradley *et al* (1979), who showed not only that the assumptions underlying correction for continuity in most empirical situations are untenable, but also that for a nominal α level of 0.05, even with very small (fractional) expected frequencies, in practice the actual Type 1 error rate seldom exceeds 0.06. Those authors advise caution in interpreting exact α levels, but also note that these small deviations from the true α level are seldom of much importance.

Present Pain Intensity

At the first assessment the median PPI score was 1 (SIR 1.0) and at the second 0 (0.6). Change in PPI scores was not significantly related to change in psoriasis severity (χ^2=2.07, *df*=2), but this is not particularly surprising since scores were so low on this measure.

Pain Rating Index - Total.

The pain rating scales can be combined to form the PRI-T scale. The mean score at the first assessment was 8.43 (8.89, 0 to 39) and at the second was 4.35 (5.47, 0 to 20), which results in a mean change over assessments of −4.18 (9.72, −37 to +17). These distributions are positively skewed. The median rating on this scale was 6 (SIR 4.5) at the first assessment and the 2.5 (3.5) at the second.

Once the starting level of this variable has been taken into account, area of coverage, change in area of coverage, and time since onset all predicted PRI-T scores at time 2, and there was a significant interaction between time since onset and the sex of the subject. The regression estimates and analysis of variance are summarised in Table 5.8. The regression model had an R^2 value of 0.55 and the residuals were normally distributed (Filliben correlation coefficient = 0.97).

Table 5.8 Summary of estimates and analysis of variance for regression of total pain rating index scores at time 2 on five predictor variables.

Parameter	*Estimate*	*SE*	*t*	*Sig p<*
(Constant)	0.66	2.00	0.33	-
Sex (males=0, females=1)	7.34	2.89	2.54	0.02
PRI-T score at time 1	0.20	0.088	2.30	0.05
Area of coverage at time 2	0.24	0.21	1.13	-
Change in area of coverage	0.87	0.25	3.45	0.05
Time since onset	0.091	0.084	1.09	-
Time since onset × Sex	−0.30	0.11	−2.62	0.02

Analysis of Variance

Source	*df*	*SS*	*MS*	*F*	*Sig p<*
Regression	6	542.78	90.46	5.51	0.001
Residual	27	442.98	16.41		
Total	33	985.76			

Pain Rating Index - Sensory

The median score on this subscale at the first assessment of 4 (3.0, 0–19) compared with 2 (3.0, 0–12) at the second. The χ^2 value of 12.53 is significant at the 0.02 level suggesting that this distribution was unlikely to have occurred by chance. Examination of the cell patterns in Table 5.9 reveals that most of the χ^2 total can be accounted for by the cell corresponding to psoriasis worsening and PRI-S increasing. That is, if psoriasis worsened between assessments then more, or more severe, pain descriptors were used to describe the pain or discomfort associated with psoriasis.

Table 5.9 Contingency table of psoriasis change and PRI-S change between two assessments (expected values in parentheses)

PRI-S Score	*Psoriasis Severity* Improved	Worsened
Increased	2 (5.88)	6 (2.17)
No Change	3 (2.21)	0 (0.79)
Decreased	20 (16.91)	3 (6.09)

Pain Rating Index - Affective.

Although the range of ratings for the affective subscale changed from 0–12 at the first assessment to 0–5 at the second, the median ratings stayed the same (0, SIR 0) at both assessments. The small number of ratings made in this category (8 at the first assessment and only 4 at the second) make useful analysis impossible.

Pain Rating Index - Evaluative.

The median score at the first assessment of 1 (1.0, 0–5) was slightly higher than at the second of 0 (0.5, 0–5). The value for χ^2 was 10.11 which is significant at the 0.05 level. Examination of the cell distributions in Table 5.10 reveals that once again the cell which contributes most to the total χ^2 value is where psoriasis worsens between assessments and PRI-E scores increase. Thus, worsening psoriasis is associated with more individuals choosing a word in this category (the PRI-E subscale is based on one category of descriptor words) or choosing a word with a higher ranking in this category.

Table 5.10 Contingency table of psoriasis change and PRI-E change between two assessments (expected values in parentheses)

PRI-E Score	*Psoriasis Severity* Improved	Worsened
Increased	0 (2.21)	3 (0.79)
No Change	15 (14.71)	5 (5.29)
Decreased	10 (8.09)	1 (2.91)

Pain Rating Index - Miscellaneous.

The median scores on this scale stayed the same at both assessments (both zero, SIRs 0.5 and 0) but the range at the second assessment of 0–3 was narrower than at the first (0–7). The value for χ^2 was 11.01 which is significant at the 0.05 level of significance, and once again the cell that accounts for most of this value is where both psoriasis and PRI-M ratings worsen between assessments (Table 5.11).

Table 5.11 Contingency table of psoriasis change and PRI-M change between two assessments (expected values in parentheses)

PRI-E Score	*Psoriasis Severity* Improved	Worsened
Increased	0 (2.94)	4 (1.08)
No Change	15 (13.24)	3 (4.77)
Decreased	10 (8.82)	2 (3.18)

5.7 **Discussion**

The general reaction of subjects to the questionnaires and SKINMAP was good: all completed the questionnaires, although several subjects missed individual questions, or occasionally a whole page. These omissions were rectified immediately, and the subjects indicated that they were simply missed, rather than deliberately avoided. On the second assessment, subjects were told that they were not expected to remember their original responses to the questionnaires, and asked whether they thought they could remember what they had previously written. All subjects indicated that they doubted they could remember, and given the interval of three months, this seems likely. In any event, they were instructed to complete each questionnaire as directed.

It is possible that administration of SKINMAP prior to completing the questionnaires may in principle have influenced the results. However, if this were the case it would have been apparent in the most context-sensitive measure employed - state anxiety. As can be seen from the scores on this scale, levels were close to reported norms for control subjects. It is unlikely therefore that the results reported here were influenced by this procedural factor.

The distribution of areas of coverage at both assessments shown in Figure 5.1 confirms that the group in this study did indeed have more severe psoriasis than the group in the previous study. Although the mean area of coverage in both studies is quite similar, the larger standard deviation in the first study suggests that the distribution of areas of coverage was very highly positively skewed. In the present study, while the distribution is still positively skewed, more subjects had significant psoriasis (at the first assessment) than before. Nevertheless, the mean total area of coverage of 4.2% is still quite low.

Slightly more females were represented in the sample, but the mean ages for males (44.8, SD 17.2) and females (46.8, 18.5) were not significantly different. Similarly, the mean time since onset for males (22.0, 14.4) was not significantly different from the mean for females (24.3, 14.7).

5.7.1 **Depression and psoriasis severity**

It was not expected that depression scores for the group would reach clinical levels and this was confirmed by the results. The mean scores of 3.3 at the first assessment and 3.5 at the second are both well below the cutoff point of ≥8 on the HADS. This supports the findings of the first study where depression levels were higher than controls but still within 'normal' limits. However, as hypothesised, depression scores at the second

assessment were significantly associated with change in disease severity (Table 5.1). There was a significant interaction with sex, which shows that the relationship between depression and disease severity is different for males and females. Regression equations for males and females are generated by substituting first the code of 0 (for males), then the code of 1 (for females) into the 'sex' variable and interractions in the full model. Using the coefficients from Table 5.1, the regression equation for males can therefore be expressed as:

$$\mathbf{Dep_2 = -0.55 + 0.52 \times Dep_1 - 0.065 \times Area_2 + 0.86 \times Change + 0.10 \times Time\ since\ onset}$$

where $\mathbf{Dep_1}$ is depression at the first assessment and $\mathbf{Dep_2}$ is depression at the second assessment (in HADS scores), $\mathbf{Area_2}$ is area of coverage at the second assessment (expressed as percentage body coverage), **Change** is change in percentage area of coverage between the first and the second assessments, and **Time since onset** is expressed in years. For females the regression equation is:

$$\mathbf{Dep_2 = -0.94 + 0.52 \times Dep_1 + 0.415 \times Area_2 + 0.10 \times Change + 0.10 \times Time\ since\ onset}$$

It can be seen that, while time since onset of psoriasis has the same effect in both sexes, male depression scores are much more strongly related to change in area of coverage than female depression scores. Furthermore, for both males and females, the longer the individual has been suffering, the greater the depression. With a coefficient of 0.10, this means that (keeping all other variables constant) for every 10 years a subject has been suffering from psoriasis the model predicts approximately a one point increase in depression scores. This is in contrast to the first study where depression scores were not related to time since onset at all. In practical terms this means that, for a given starting level of depression, depression in males will vary more than females as their psoriasis fluctuates. These fluctuations in depression will tend to be more marked for those who have been suffering psoriasis the longest.

There is a well documented sex difference in prevalence rates for depression, with women outnumbering men in the ratio of approximately 2:1 (e.g. Weissman & Klerman, 1977). While the numbers of possible cases identified in the present study were very small, they do follow a similar pattern (2 females and 1 male at the first assessment, 4 females and 1 male at the second). This is reflected in the median depression scores for males and females, where males had a median score at the first assessment of 2 and a median of 1 at the second assessment, compared to medians of 4 at both assessments for females. This general difference in depression levels may in part explain the different models for males and females. The difference in the model lies in the rela-

tionship between coverage at time 2 and change in coverage between times 1 and 2. While it is not possible to tell from the data, one explanation of the different models is that lower levels of depression fluctuate as a function of change in area of coverage, while higher levels are more sensitive to absolute area of coverage: that is, the difference is in levels of depression, not between sexes.

The second point of interest is the relationship between time since onset and change in depression scores. Explanation of this phenomenon depends upon the direction of causality between depression and psoriasis. If depressed mood is a *consequence* of psoriatic relapse, change in depression scores at this level may be related to perceptions of the likely course of the condition: perceptions which would be reinforced over a period of years as the sufferer becomes more aware of phasic fluctuations. If, on the other hand, psoriasis relapse is contingent upon prior increase in depression an explanation is less obvious, and requires some external factor to trigger the depression, possibly unrelated to psoriasis. Of course, it is also possible that an independent external trigger may influence depression *and* psoriasis activity, and that the two are essentially unrelated. A prospective study using a time-series design over several months, if not years, would be required to clarify this issue.

To summarise, depression at the second assessment in females is weakly related to change in area of coverage, but strongly related to absolute area of coverage, while in males, this pattern is reversed. Time since onset is a significant predictor for males and for females.

5.7.2 **Anxiety and psoriasis severity**

The first study showed psoriasis sufferers scoring higher than controls on trait anxiety, and higher than the published norms. In the present study, the mean score of 7.6 on the HADS at the first assessment and 7.1 at the second show this group to be somewhat less anxious than the psoriasis outpatient groups reported by Price *et al* (1990), who found mean scores on the same instrument for all except one group ranging between 8.09 and 9.17. (Their psychotherapy group at 6 month follow-up scored a mean of 7.0). While scores of around 7 are slightly below the cutoff point of ≥8 for possible clinical anxiety, they are nevertheless still quite high. The HADS measures anxiety *over the past week*, so these figures are not likely to be related to anxiety caused by testing.

In the present study the hypothesis was that anxiety at the second assessment would be related to change in disease severity once initial levels of anxiety had been taken into

account and this was supported by the data. Unlike depression, there are no significant differences between males and females. The R^2 value of 0.75 is high, suggesting that the simple model is a relatively good representation of the true relationship. From the coefficients summarised in Table 5.2, the model for the relationship between psoriasis and anxiety can therefore be expressed as:

$$\mathbf{Anx_2 = -1.31 + 0.88 \times Anx_1 + 0.21 \times Area_2 + 0.53 \times Change + 0.076 \times Time\ since\ onset}$$

where $\mathbf{Anx_1}$ is anxiety at the first assessment and $\mathbf{Anx_2}$ anxiety at the second (in HADS scores). As with depression, change in anxiety is positively related to change in area of coverage, and the time since onset of psoriasis.

The predominating *type* of anxiety reaction does not vary at all between assessments and is not associated with change in area of coverage for either males or females. The ratio of cognitive to somatic symptoms does not change either. This would support the concept of an individual response stereotypy (Lacey & Lacey, 1958) that is relatively resistant to change which underlies the cognitive/somatic anxiety distinction. The mean ratio of cognitive to somatic symptoms is 1.08, which corresponds to a mean ratio of 1.03 for both psoriasis sufferers and controls in the previous study. However, while the ratio of cognitive to somatic symptoms in controls and psoriatics was the same, it should be noted that psoriasis sufferers did in fact score higher on *both* scales than controls. The scores found in the present study broadly concur with those found in the first study, and confirm that psoriasis sufferers tend to report both more cognitive *and* more somatic symptoms of anxiety when in an anxious situation than controls.

To summarise, anxiety levels at the second assessment are positively related to change in area of coverage, absolute area, and the time since onset of psoriasis. The ratio of cognitive to somatic anxiety symptoms reported in anxious situations does not change as the severity of the condition varies.

5.7.3 **Self-esteem and psoriasis severity**

Compared with the scores for total self-esteem on this scale in the first study (137.7 for the full matched psoriasis group), the scores in the present study were moderately high (142.7 and 146.8). This is interesting, given that the group in the first study had relatively mild psoriasis. Indeed, the scores in the present study are higher than those for the matched control group previously, and higher than the score of 137 reported for "normal controls" by Robson (1989).

However, of more interest than absolute levels is the change in self-esteem scores that occurred between assessments. The mean change was modest (4.0), but when related to

disease severity there was a significant relationship between change in area of coverage and change in total self-esteem score, and there was a difference between males and females in the extent to which this relationship holds. For males, self-esteem rises dramatically as psoriasis ameliorates, while for females, although the trend is in the same direction, the degree of change is much less pronounced. Using the coefficients summarised in Table 5.3, the relationship between self-esteem at the second assessment and psoriasis severity for males can therefore be expressed as:

$$\mathbf{SEQ_2 = 28.54 + 0.85 \times SEQ_1 - 0.93 \times Area_2 - 5.90 \times Change}$$

while for females the model is:

$$\mathbf{SEQ_2 = 24.95 + 0.85 \times SEQ_1 - 0.93 \times Area_2 - 1.00 \times Change}$$

and the R^2 value of 0.71 suggests that it fits the data quite well.

Self-esteem is not related at all to the length of time the individual has been suffering from psoriasis. Self-esteem in psoriasis sufferers may therefore be related more to general self-perceptions rather than linked to anticipation of the likely progress of the disease, and as such relate more directly to disease fluctuation than to learned responses.

Perhaps the most interesting of the SEQ subscale results was that for *competence, resilience and control*, where change in area of coverage between assessments predicted scores at time 2 once the starting levels had been taken into account. Greater changes in area of coverage corresponded to greater changes in subscale scores, where the better the psoriasis became, the higher the score on this subscale. Scores were significantly greater the longer the time since onset of psoriasis. This subscale taps how much control respondents feel they have over their lives and its increase as psoriasis decreased suggests that this facet of self-esteem is linked to the effectiveness of the treatment for psoriasis: if psoriasis is ameliorating, subjects feel they have more control over their lives.

The *attractiveness* subscale produced clear but interesting results. Once starting levels of attractiveness had been taken into account, levels at time 2 were significantly predicted by change in area of coverage: the better the psoriasis became the higher the attractiveness score but this was much more pronounced for men than for women. For example, for equal starting levels, a 20% decrease in area of coverage for males predicts an increase of 4.4 in attractiveness rating, while for females the same change in area of coverage predicts only a change of 0.2 in attractiveness rating. Males are therefore more

susceptible to change in how attractive they think they are, related to the severity of their psoriasis, while women's ratings do not change as the disease fluctuates.

The only other scale which shows a relationship with change in area of coverage is the *value of existence* subscale, where decrease in psoriasis predicts increase in subscale scores for males and females to the same extent. This scale taps issues like "I am glad I am who I am", and "It's pretty tough to be me", and as such is perhaps closest to the traditional conception of self-esteem as self-evaluation.

To summarise, there is a clear relationship between change in area of coverage and self-esteem, which is more apparent for males than for females.

5.7.4 **Sleep quality and psoriasis severity**

The Nottingham Health Profile used in the previous study showed that sleep problems are associated with psoriasis. This has also subsequently been found by Finlay *et al* (1990) using the Sickness Impact Profile. Responses to the Patient Knowledge interview reported in Chapter 4 also suggested that sleep is a problem, particularly when the condition is severe. The PSQI was used in the present study to discover exactly what the sleep problems are and to quantify how they vary as the severity of the condition varies.

The mean total PSQI score at both assessments was approximately 5.7, which falls between a score of 2.7 for "normal controls" and 11.1 for "depressives" reported by the originators of the questionnaire (Buysse *et al*, 1989). As a group, then, psoriasis sufferers have relatively poor sleep. The regression model is interesting because it indicates that, while total sleep quality scores at time 2 are predicted by change in area of coverage (the better the psoriasis becomes, the better the reported sleep quality), there is a sex difference in the effect of time since onset. From the regression coefficients in Table 5.7, the regression model for males is:

$$\mathbf{PSQI_2 = -2.42 + 0.85 \times PSQI_1 + 0.078 \times Area_2 + 0.24 \times Change + 0.12 \times Time\ since\ onset}$$

while for females the model is:

$$\mathbf{PSQI_2 = 1.62 + 0.85 \times PSQI_1 + 0.078 \times Area_2 + 0.24 \times Change - 0.01 \times Time\ since\ onset}$$

and it can be seen that the parameter estimate for time since onset for females has little effect while the estimate for time since onset in males is quite high.

It is interesting that there was no relationship between change in disease severity and any of the PSQI subscales. Scores on these subscales were generally on the low side, suggesting that the majority of subjects did not have specific sleep problems which could be identified as a group trait. The relatively high global PSQI score must therefore be interpreted as a *general* poor sleep quality, rather than poor sleep quality due to some disease-specific factor.

5.7.5 Pain and psoriasis severity

Pain is not usually associated with psoriasis, but studies have often used pruritus as part of an assessment of disease severity (Chapter 2). The purpose of including the MPQ in the present study was to examine further the pain or discomfort that psoriasis sufferers experience from their condition and to ascertain whether this changes as the disease changes. The instructions for the MPQ were worded such that only pain (or discomfort) from *psoriasis* was reported, not pain from any other condition that the respondent might have.

Given the generally low scores on the PPI, which measures the degree of pain on a five point scale, it is perhaps not surprising that change on this scale showed no relationship with change in area of coverage for either males or females. However, change on three of the four sub pain-rating indexes was significantly associated with change in area of coverage. These scales are designed to tap the qualitative nature of the pain experience and as such can provide a useful means of describing the type of pain experienced for any condition.

Table 5.12 PRI-S descriptions of psoriasis pain. Percentages of subjects who chose various words on two assessments

Descriptor	*Percentage of subjects who chose this word at assessment 1*	*Percentage of subjects who chose this word at assessment 2*
Itchy	74.3	44.1
Sore	25.7	20.6
Tender	22.9	23.5
Burning	20.0	8.8
Pricking	14.3	5.9
Hot	11.4	8.8
Stinging	2.9	11.8

The *sensory* scale is concerned with how the pain actually *feels* and produces scores in the range 0 to 42, although this range is somewhat artificial since the aim is to *describe*

pain, and the words in each category ought not to apply to all conditions. Examination of the actual words chosen in the sensory category provide a more precise description of the sensory pain experience of psoriasis than has hitherto been available. Table 5.12 lists those words which were chosen by more than 10% of the sample at one assessment. The most frequently used word to describe the sensory component of psoriasis pain is "itchy", but over 20% of respondents also described it as "sore" and "tender" at both assessments, and as "burning" at the first assessment. Of course, it is not clear whether these descriptors refer to actual psoriasis or to the effects on the skin of treatment. PUVA treatment, for example, can sometimes result in generalised skin burning, and dithranol-based topical treatments tend to irritate unaffected skin with burn-like effects.

While the numbers in individual cells of the contingency tables 5.9 to 5.11 are relatively small, the χ^2 values confirms that these distribution was unlikely to have occurred by chance. By far the biggest influences on this are the high number of subjects in the group whose psoriasis worsened between assessments whose PRI-S score also worsened, and the low numbers in the group whose psoriasis worsened but PRI-S improved. This suggests that the sensory pain rating index of the McGill Pain Questionnaire is quite sensitive to fluctuations in psoriasis severity.

This pattern is reflected in the *evaluative* pain rating index, which suggests that that subscale is also sensitive to psoriasis change. It is interesting that 17 subjects at the first assessment and 11 at the second elected to tick a word in this category, and that the strength of evaluation was so intense. Two subjects at the first assessment even ticked the word 'unbearable' which represents the highest rank on this subscale (see Table 5.13), while the full range of 0–5 was also used at the second assessment. This suggests that pain may be of major importance to at least some psoriasis patients.

Table 5.13 PRI-E descriptions of psoriasis pain. Numbers of subjects who chose various words on two assessments. These words represent the complete 'evaluative' scale

Descriptor	*Number of subjects who chose this word at assessment 1*	*Number of subjects who chose this word at assessment 2*
Annoying	6	7
Troublesome	6	1
Miserable	3	1
Intense	0	1
Unbearable	2	1

The *affective* subcategory is concerned with how sufferers *feel* about their pain or irritation, and there was a significant relationship between change in area of coverage and change on this subscale. The only word that was chosen by more than 10% of respondents was "tiring" (14.3% at the first assessment, 5.9% at the second). The *evaluative* subscale is based on one category only. Twenty percent of respondents chose "troublesome" at the first assessment and 17.1% chose "annoying", while only 2.9% chose "troublesome" at the second and 20.6% chose "annoying". It would appear therefore that decrease in area of coverage results in a more favourable evaluation of pain.

The simple measurement of pruritus sometimes employed to describe irritation from psoriasis is not an adequate description of the type of pain experienced by psoriasis sufferers, and more extensive inquiries into the nature of sensory pain may provide a fuller description than has hitherto been available.

When all these scales are combined into the total pain rating index score, there is a highly significant relationship with change in area of coverage and time since onset, with significant differences between males and females. From the regression coefficients in Table 5.8, the model for males is:

$$\textbf{PRI-T}_2 = 0.66 + 0.20\times\textbf{PRI-T}_1 + 0.24\times\textbf{Area}_2 + 0.87\times\textbf{Change} + 0.091\times\textbf{Time since onset}$$

while for females the model is:

$$\textbf{PRI-T}_2 = 8.00 + 0.20\times\textbf{PRI-T}_1 + 0.24\times\textbf{Area}_2 + 0.87\times\textbf{Change} - 2.909\times\textbf{Time since onset}$$

The effect of time since onset is in opposite directions for men and women, and the coefficient for females is quite large.

The total pain experience, then, has been shown to comprise more than simply pruritus, and when taken as an overall description of change in the *quality* of pain, there is a significant decrease for both men and women as area of coverage recedes.

5.8 Summary and conclusions

The most striking finding to emerge from this investigation is that there are significant differences between males and females in the relationship of psoriasis severity to psychological factors. Roenigk & Roenigk (1978) examined this idea in the late seventies and reported that females are more psychologically affected by psoriasis than males, which they interpreted as a reaction to sex-role conditioning: "a girl [is] on the

look-out for the male to depend upon" (p.531). Times, and gender-role stereotypes, have changed, and in the nineties it is no longer tenable to attribute higher psychological distress over visible deformity in women to reduced chances of catching a mate! Previous investigations into the relationship between depression, anxiety and psoriasis have produced conflicting results, and most have been concerned with hospitalised patients. The present study has shown a significant relationship between *change* in disease severity and change in depression and anxiety levels. Thus, while psoriasis sufferers may be only marginally more depressed and more anxious than non-sufferers, when the starting levels of these variables are taken into account, they can be significantly predicted by change in area of coverage. Time since onset is an influencing factor in depression levels for males where the longer the patient has been suffering, the greater the influence on depression.

Self-esteem improves significantly as the psoriasis improves, more so for men than for women, and when the individual components of self-esteem are examined, *competence, resilience and control, attractiveness,* and *value of existence* show significant improvements as psoriasis ameliorates. The most striking factor with self-esteem is that change seems to be much more apparent in men than women. Change in subjective sleep quality is also related to change in area of coverage, and descriptions of the quality of pain experienced also show significant improvement with psoriasis improvement.

This study has shown that by using a within-subjects design, changes in psychological variables can be related to changes in the severity of psoriasis. This has not previously been demonstrated in the cross-sectional studies reviewed in Chapter 1, and the data reported here support the hypothesis that the psychological state of psoriasis sufferers is directly related to the state of their psoriasis.

Chapter Six

General Discussion

6.1 Overview of the research

The literature review in Chapter 1 led to some general hypotheses concerning a link between certain psychological variables and psoriasis. First, both Hughes *et al* (1983) and Wessely & Lewis (1989) had found high prevalence of psychiatric "cases" in general dermatology patients. They did not provide figures for the prevalence of cases in psoriasis sufferers specifically. The first hypothesis therefore was that the prevalence of psychiatric cases in a group of psoriasis sufferers would be greater than in a group of matched controls.

Second, a number of studies had found levels of depression in hospitalised psoriasis sufferers significantly higher than other in-patients (e.g. Fava *et al*, 1980, Lyketsos *et al*, 1985). Relatively little work, however, has been done to assess levels of depression in groups of psoriasis sufferers whose disease was not severe enough to warrant hospitalisation, but who represent the majority of psoriasis sufferers. What evidence there is is inconclusive. Hardy & Cotterill (1982) had found a small group of out-patient psoriasis sufferers (predominantly female) scoring borderline on the Beck Depression Inventory, but Price, Mottahedin & Mayo (1991) had found levels in out-patients well below the cutoff point of ≥8 on the HADS.

Since hospitalisation for therapy implies quite severe psoriasis, from these results the second hypothesis was that psoriasis out-patients would have higher levels of depression symptoms than matched non-sufferers, and probably also that the level of depression symptoms would tend be correlated with the severity of the psoriasis. Thus, for those psoriasis sufferers whose disease was in a relatively clear phase, levels of depression symptoms would approximate those of controls, while levels in sufferers whose disease was more active would be raised.

The third, related hypothesis concerned levels of anxiety in psoriasis sufferers. Both Fava *et al* (1980) and Lyketsos *et al* (1985) had found anxiety in hospitalised patients higher than hospitalised controls, but as with depression, little research had examined levels of anxiety in out-patient populations. Price *et al* (1991) found outpatients' mean scores above the HADS cutoff point and also provided some evidence that levels of anxiety tended to fluctuate with psoriasis severity, but their measure of severity was inadequate to draw any firm conclusions. Similarly, the study reported by Gaston *et al* (1987) found a significant relationship between anxiety and psoriasis severity, but those authors measured psoriasis on the scalp only. The specific hypothesis regarding anxiety

therefore was that psoriasis outpatients would have higher levels of anxiety than matched controls, and that levels of anxiety in psoriasis sufferers would tend to be correlated with psoriasis severity.

Self-esteem in psoriasis sufferers, has been touched on indirectly by Ginsburg & Link (1989) in their study of feelings of stigmatisation associated with psoriasis, but most of the evidence for low self-esteem is anecdotal (e.g. Jobling, 1976; Stankler, 1981). Ginsburg & Link found age at onset of psoriasis positively related to some of their stigma factors, and time since onset of psoriasis negatively related. They also found extent of bleeding of the psoriasis to be the best predictor of feelings of stigmatisation. The third specific hypothesis therefore was that self-esteem in psoriasis sufferers would be lower than in matched controls, but that this would be moderated by the age at onset (the younger the age at onset the lower the self-esteem), the time since onset (the longer the time since onset the higher the self-esteem), and the severity of the condition (the worse the psoriasis, the lower the self-esteem). Individual components of self-esteem were examined on an exploratory basis.

The next area of study was derived from an overview of the literature regarding psoriasis and psychological variables, which had suggested that patients were acutely aware of their symptoms. Thus, it was suggested that psoriasis sufferers would report lower perceived health status than matched controls. Individual elements of subjective health status were to be examined also, but on an exploratory basis.

Two further areas were examined in detail, both of which arose as a result of findings while the research was under way. It became quite clear from informal conversations with psoriasis sufferers in the first study that there was a wide range of lay beliefs and knowledge about psoriasis which had not been examined in any detail. Savin (1970) and Burton & Thompson (1976) had made broad attempts to tap this data but no detailed study had examined lay beliefs and knowledge about psoriasis. Lay beliefs are important determinants of health behaviour (e.g. Rosenstock, 1974) and form an important part of understanding any disease. The study reported in Chapter 4 was therefore undertaken to explore these beliefs and knowledge in detail.

Finally, while reviewing the available means of measuring psoriasis severity, it became clear that no valid and reliable method existed for measuring the area of skin affected that did not require expensive equipment and specialised training. A computer program was therefore designed to aid in the assessment of dermatological disease severity, and its development and validation were reported in Chapter 2.

6.2 Performance of SKINMAP

The first task was to evaluate the validity and reliability of existing means of *measuring* psoriasis severity, and this was reported in Chapter 2. The concept of "severity" in psoriasis is defined by the purpose of the research, and while it was noted that typical clinical signs such as thickening and erythema are often recorded as part of a measure of severity, *all* assessment techniques include some estimate of the area of coverage in one form or another. Area of coverage in psoriasis is most often visually assessed, but it was shown in Chapter 2 that research into area perception showed that visual area estimation was likely to be inaccurate and inconsistent when applied to the area of disks (as in psoriasis), and that this had been confirmed in a clinical setting by comparing dermatologists' estimations of area of coverage with planimetrically assessed area. Other means of directly measuring area of coverage were discussed, but they all involved either specialised and expensive equipment, or required the subject to be in a standardised environment.

However, while estimating area is unreliable, evaluating the equivalence of two disks is much less so. When asked to provide an area estimation subjects fare poorly, but when asked to match one disk to another, subjects fare well. A computer program, called SKINMAP, was therefore developed which allowed psoriasis to be mapped onto standard body shapes by matching lesions drawn on the computer with those on the patient's body. The area of coverage is then calculated by SKINMAP. A study of the validity of SKINMAP showed it to provide significantly more accurate and consistent estimates of area of coverage than visual estimation, and accordingly it was used throughout the research presented in this thesis.

During the course of this research SKINMAP has been used with over 100 psoriasis sufferers and no adverse reactions to it were noted at all. It is slightly more time consuming than simple visual estimation, but none of the sufferers reported this to be a problem: indeed many of them seemed to welcome the opportunity to show their psoriasis and talk about it in great detail. Often subjects would spontaneously give an account of the vicissitudes of a particular patch while I mapped the body region. Several also actually seemed pleased that more notice was being taken of their skin than a cursory visual inspection.

Regular use of SKINMAP revealed some minor problems and suggested some possible refinements. For example, when SKINMAP saves patch location and size information to a temporary file after each body region, it saves *all* the data from the current session. Thus, for a patient with many psoriasis patches on several areas of the body, as the

session progresses so disk access time increases. In a few patients this was quite noticeable, and it would be better to have data from each region stored independently. This will be taken into account in future versions of SKINMAP. One problem that also became apparent in regular use was that the strategy of presenting all body regions for all patients was perhaps over-cautious. This strategy had been followed so as to avoid the problem of missing certain body regions, but in practice it meant that all body regions had to be drawn, even if the subject only had psoriasis on their face, for example, which was the last body region, or in order to produce a record of no psoriasis involvement at all. This was quite time-consuming and selection of body regions from a menu will therefore be incorporated as an option into later versions. Finally, while output of the full database file in pre-defined format for direct entry into SPSSx worked well, the output routines proved to be inadequate if only selected cases needed to be accessed. These output routines will therefore be enhanced in future versions.

To summarise, the SKINMAP computer program overcomes problems with visual area estimation and provides a means of measuring psoriasis which is both accurate and consistent, and which is acceptable to the patient. It worked well in practice, but some minor refinements will be made for future versions.

6.3 **Generalisability of results**

There would be little point examining psychological factors associated with psoriasis in groups of subjects which were not representative of the wider psoriatic population. The procedure used to select subjects for the studies reported in this thesis involved contacting patients who were currently being treated, or who had previously been treated for their condition in a hospital outpatient department. The rationale for this approach was that patients hospitalised for their condition would be more likely to be experiencing higher levels of depression and anxiety than those not hospitalised, and as such may not accurately reflect the psychological state of the majority of sufferers, who treat their condition at home, or on an outpatient basis. Also, psoriasis sufferers presenting at GP's surgeries were not chosen as a sampling frame, first because suspected cases of psoriasis are generally referred to a hospital dermatologist for confirmation of diagnosis, and second because the logistical considerations of extracting data from a large number of GPs records would have been prohibitive, whereas the catchment area of the dermatology department was large and the identification of patients was facilitated by existing procedures.

The question then arises whether the characteristics of the groups reported in this thesis match those of the whole psoriatic population. The most extensive study on the characteristics of psoriasis patients in the general population comes from Hellgren's (1967) survey of psoriasis in Sweden. In Hellgren's study prevalence in males was consistently higher than in females in all geographical areas, when age had been taken into account. There were more females than males in both the studies reported here, which may have influenced the results - particularly with psychological factors where sex is an important predictor of prevalence (e.g. depression). To counter this, results were calculated for males and females separately, as well as the whole group, and these figures have been reported where appropriate. Hellgren reports mean age at onset for males between 25.2 (SD 18.6) and 34.3 (20.8), depending on geographical area, which compares with 31.0 (17.1) in the first study and 23.8 (13.8) in the second. For females, Hellgren reports mean age at onset between 20.4 (15.6) and 32.7 (21.9) which compares with 24.6 (16.1) in the first study and 22.5 (17.1) in the second. Therefore the patients used in the present research are representative of the general psoriatic population with regards to age at onset. Since the mean age at time of study in Hellgren's groups is similar to the mean ages in the present studies, the mean time since onset will also be similar.

The areas of coverage in the present studies is considerably higher than the mean area of coverage in Hellgren's sample. Hellgren reported only estimates of absolute area of coverage and not percentage of total body coverage. The mean coverage was 78.2cm^2. Without any indication of the total skin area of the individual sufferers it is not possible to convert this figure accurately into percent body coverage, but an approximation can be calculated by dividing by an average body area of 19355cm^2 (Tortora & Anagnostakos, 1987). This gives an estimated mean area of coverage of 0.4%, compared with the median in the first study of 1.4% and in the second study 2.5% (first assessment) and 1.6% (second assessment). This difference is almost certainly because of the sampling frame used. Hellgren examined a representative sample of the complete Swedish population including psoriasis sufferers whose condition was either not severe enough for outpatient treatment, who were self-medicating, or may not have been previously diagnosed.

Thus, the subjects used in the studies reported in this thesis have similar age at onset and length of suffering to those in Hellgren's epidemiological study, but the sex ratio is reversed and the area of coverage greater than what would be expected in the full psoriatic population. Sex differences were allowed for by using sex as an independent variable in the analyses. The difference in mean areas of coverage can be explained by the very large sample size in Hellgren's study.

The questionnaires were selected for each variable from what was often a wide available range. The criteria for selection have been discussed in the appropriate chapters. The main concern for the prospective investigation reported in chapter five was a possible re-test artifact (Jorm, Duncan-Jones & Scott, 1989) that tends to occur with some measures used in longitudinal research. The re-test artifact that Jorm *et al* and others (e.g. Bromet *et al*, 1986) have reported concerns the tendency for scores on some questionnaires to be consecutively lower on repeated administration. Jorm and his colleagues point out that this must be artifactual otherwise psychiatric disorders would tend to decrease in prevalence over time, and they note that if a re-test artifact occurs, interpretation of results becomes problematic. Jorm's paper was therefore concerned with isolating those aspects of questionnaires which are associated with the re-test artifact. Jorm *et al* suggest from examining responses to an epidemiological study that two factors must be present for the re-test artifact to occur: oral administration of the test and a test that measures negative self-characteristics. While some of the measures used in the research reported here necessarily involved measurement of negative self-characteristics (the measurement of self-esteem for example), all were presented as pen-and-paper tests, and all were completed anonymously by respondents. It is not likely therefore that a re-test artifact will be a problem with the current data.

6.4 **Discussion of the main findings and suggestions for future research**

6.4.1 **Psychiatric morbidity**

Two studies reviewed in Chapter 1 found a high rate of probable "cases" on the GHQ among dermatology patients. Hughes, Barraclough, Hamblin & White (1983) found 30% of their outpatients scoring above the GHQ cutoff point while Wessely & Lewis (1989) reported 43%. This compares with 24% in the psoriasis group reported in Chapter 3 and 24% in the control group. There were no differences between the psoriasis and control groups on the total GHQ or on any of the subscales. This discrepancy is almost certainly because both Hughes' and Wessely & Lewis's samples comprised a range of dermatological conditions including psoriasis, some of which are more likely to be associated with psychiatric morbidity (e.g. *dermatitis artefacta*), and which fall higher on Rook's (1972) hierarchy of psychosomatic involvement discussed in Chapter 1.

Thus, while dermatology outpatients in general (including psoriasis patients) show higher prevalence of cases than controls, taken as a group on their own, psoriasis outpatients show psychiatric morbidity levels comparable to non-dermatology controls.

6.4.2 **Depression.**

While there is some evidence that hospitalised psoriasis patients are more depressed than controls (e.g. Goldsmith, Fisher & Wacks, 1969; Fava *et al*, 1980; Lyketsos *et al*, 1985), there is sparse evidence that this is also the case with non-hospitalised patients. Hardy & Cotterill (1982) found a small group of psoriasis outpatients to have a mean BDI score of 9.1, which is just below the cutoff point of 10 for minimal/mild depression, while Price, Mottahedin & Mayo (1991) found mean depression scores on the HADS of between 3.1 and 4.8 (depending on group), which is well below the cutoff point of 9. In the present research, the mean scores on the HADS at both assessments in the prospective study (3.3 and 3.5) correspond to those found by Price *et al*, and suggest that as a whole, the groups were not clinically depressed. The results from the cross-sectional study reported in Chapter 3 however, did show psoriasis sufferers reporting significantly more depressive symptoms than controls with a mean CES-D score of 11.2. While this is higher than the mean score for controls (8.6), it is below the cutoff point of 16 for possible depression. Nevertheless, more psoriasis sufferers (26%) scored above the cutoff point than controls (16%).

Taking these results together, psoriasis sufferers not hospitalised for their condition have higher levels of depression symptoms than non-sufferers, but these do not generally reach the level of clinical significance.

Studies which relate depression levels or the prevalence of depression symptoms to psoriasis *severity* are also sparse. Only Gupta *et al* (1991) has attempted to relate the starting levels and change in psoriasis severity to depression scores, and while they did show improvement in depression scores with improvement in psoriasis, no information was given about how area of coverage was assessed, and their sample comprised inpatients only. Patients hospitalised for any reason are likely to be more depressed than those not hospitalised for the same condition (Chapter 1), so Gupta's results should be interpreted with caution.

There was no relationship between area of coverage and depression in the cross-sectional study reported in Chapter 3, but this may have been because the psoriasis was generally quite clear. In the prospective study however, there was a clear relationship between disease severity and depression levels. Depression at the second assessment was evaluated once levels at the first assessment had been taken into account - that is, there was a significant relationship between *change* in area of coverage and *change* in depression scores.

However, there was a also significant difference between males and females in the extent to which this relationship held: the coefficient for change in area of coverage for males was 0.86 while for females it was 0.10, suggesting that change in area of coverage is more strongly associated with depression scores for males. On the other hand, absolute area of coverage at the second assessment was a significant predictor of change in depression scores for females but not for males. So for men, if psoriasis fluctuated (regardless of the amount of body involvement), then depression tended to fluctuate as well, but for women, the amount of psoriasis on the body determined the depression levels regardless of how much their psoriasis had changed since the first assessment. This sex difference was interpreted in terms of levels of depression: i.e. it was suggested that there may be a qualitative difference in the relationship between psoriasis severity and depression levels which is dependent upon the level of depression in general. That is, depression varies as a function of psoriasis change only when levels of depression are quite low to begin with, and varies as a function of absolute area of coverage when starting levels of depression are higher. It is not possible to test this hypothesis with Gupta's data since he neither distinguishes males and females nor reports individual areas of coverage. However, he did show that change in psoriasis severity is related to change in depression and that the greater the change in severity, the greater the change in depression.

It was suggested in Chapter 1 that a possible model of the link between depression and psoriasis severity could be drawn from social reinforcement theory (e.g. Lewinsohn, 1974). To elaborate, it has been established that individuals with overt stigmatising characteristics have poorer interpersonal relationships (e.g. Kleck *et al*, 1966), and in the case of psoriasis, based on sufferers reports (e.g. Jobling, 1976; Stankler, 1981; Jowett & Ryan, 1985) increase in disease severity may restrict interpersonal contact firstly through the simple necessity to spend so much time treating the condition, and secondly because of the anticipation of real or imagined negative reactions to the condition.

Behavioural explanations of depression are not the only framework in which these results can be interpreted. An alternative explanation of the relationship between depression and psoriasis is that depression levels may be influenced by more cognitive processes: the lack of control over the course of psoriasis may result in feelings of helplessness. It was shown in Chapter 4 that sufferers try many types of treatment on their psoriasis, but that they generally rate the effectiveness of those treatments quite poorly, and think that all treatments prescribed by doctors are simply different strengths of the same thing. This suggests feelings of helplessness about controlling psoriasis. It

is possible therefore that worsening of psoriasis may cause depression levels to rise through a learned helplessness mechanism related to previous experience with flares and remissions, and to the anticipation that treatment will have little or no effect when the disease is in an active phase. If this were the case, one would expect that the longer the patient had been suffering from psoriasis, the more likely they would be to anticipate negative results from treatment at this stage, and this conforms to the results of the regression analyses.

Conversely, patients who had long experience of psoriasis would also be more likely to recognise signs of clearing, to which they could attribute a sense of personal control. In the cross-sectional study, *absolute* depression scores were not related to time since onset. As already discussed, this may have been because the psoriasis was not particularly severe. Data from the second study however, shows there is a strong relationship between depression scores and the time since onset of psoriasis, where larger depression scores are associated with longer suffering.

To summarise, psoriasis outpatients have levels of depression higher than non-sufferers, but below the level usually considered to be clinically significant. Depression levels change as the disease progresses, with exacerbation of psoriasis corresponding to increase in depression level, and amelioration of psoriasis corresponding to decrease in depression level. This relationship is influenced by length of suffering. This has been explained with reference to both social learning theory and the learned helplessness hypothesis.

It was not possible with the study designs reported in this thesis to ascertain at what point the direction of change in depression levels is reversed. If changing area of coverage is associated with changing levels of depression, at some point the depression level must peak then begin to decline. It would be useful to follow a group of patients more closely and over a more protracted period to establish at what relative level depression stabilises (even though psoriasis severity may continue to increase), and to discover what time-lag, if any, is present between shift in disease phase and shift in rate of change of depression. It would also help to clarify the reported difference between males and females if a group could be found whose disease in both sexes fluctuated to the same degree, although that would be difficult.

6.4.3 **Anxiety**

While some authors (e.g. Fava *et al*, 1980; Baughman & Sobel, 1977) have found raised levels of anxiety in hospitalised psoriasis patients, others (e.g. Price *et al*, 1991; Gaston

et al, 1987) have shown that sufferers not hospitalised for their condition may also experience raised levels of anxiety, and the latter two authors have suggested that these levels may be related to disease severity. However, Price *et al* acknowledged that their measure of severity was unreliable, and Gaston *et al* measured severity on the scalp only. The purpose on studying anxiety in the present research therefore was first to confirm that psoriasis sufferers *are* more anxious than non-sufferers, and second to ascertain whether levels of anxiety change systematically as the disease progresses.

In the cross-sectional study reported in Chapter 3 the psoriasis group showed a small but statistically significant elevation of trait anxiety scores, with a mean approximately three points above controls, who in turn scored close to the cultural norm. There were no differences between state anxiety scores. This supports the hypotheses that psoriasis sufferers have raised levels of anxiety and is an important finding, especially given the relatively low level of psoriasis in that group. It suggests that psoriasis sufferers are more predisposed to experience anxiety whatever the current state of their condition. In the prospective study, the mean scores on the HADS were moderately elevated at both assessments but broadly corresponded with those found by Price *et al* using the same instrument. Thus, psoriasis sufferers are more predisposed to experience anxiety than non-sufferers, but the levels of anxiety reported do not reach clinical significance. Price found 26% of his sample of outpatients could be categorised as "anxious" on the HADS, which corresponds to 35% in the study reported in Chapter 5.

Area of coverage in the first study did not account for any of the variance in trait anxiety scores. This may have been because the levels of severity were low, but may also have been because individual base levels of anxiety were not considered. In the second study reported in Chapter 5, anxiety scores were significantly related to change in area of coverage scores, *and* absolute area for both sexes. This relationship was mediated by the length of time the patient had had psoriasis, with longer length of suffering being associated with greater change.

Several authors have found that psoriasis sufferers report considerable worry over the course of their condition (e.g. Jobling, 1976; Jowett & Ryan, 1985), which may give rise to a generalised heightening of feelings of anxiety not related to the current state of psoriasis. Furthermore, anxiety is commonly associated with many chronic illnesses, not only in the early stages after diagnosis, but also intermittently throughout the course of the illness (Taylor & Aspinwall, 1990). Particularly, anxiety levels tend to rise when experiencing adverse side effects from treatment (Taylor & Aspinwall, 1990) and when patients are concerned about recurrence of their condition (e.g. Welch-McCaffrey,

1985). The treatments used in psoriasis do sometimes have unpleasant side effects (skin burning and carcinoma in PUVA treatment, staining with dithranol, dehydration with retinoids) which may contribute to anxiety reactions. The cyclic nature of the condition means that individuals may experience raised anxiety even in relatively clear phases in the anticipation of relapse, and the longer that patient has had psoriasis, the more reinforcement the cyclic changes will receive.

The type of anxiety reaction was examined by the Cognitive Somatic Anxiety Questionnaire. This examines symptoms experienced by the respondent when they are feeling anxious, and as such is not a measure of anxiety levels *per se*. Scores on the cognitive or somatic subscales can be compared across groups, or the ratio of cognitive to somatic symptoms can be compared. It was hypothesised in Chapter 1 that psoriasis sufferers would exhibit a distinctive individual response stereotypy that would distinguish them from controls. In the first study, the psoriasis group reported significantly more symptoms on both scales than controls. Thus, while the ratio of cognitive to somatic symptoms in psoriasis sufferers and controls was the same, psoriasis sufferers were more aware of (or experienced more) symptoms in both categories than controls. That the ratio did not change between assessments when area of coverage did change supports the hypothesis that anxiety reactions conform to Lacey & Lacey's (1959) theory of individual response stereotype which is relatively stable over time. Further, this response appears to be a group trait which characterises psoriasis sufferers in any phase of the condition and distinguishes them from non-sufferers.

Part of the impetus behind research into the cognitive-somatic anxiety distinction was to evaluate appropriate means of treating anxiety or advising on appropriate anxiety-controlling strategies (e.g. Schwartz, Davidson & Goleman, 1978). The results of the present research has shown that psoriasis sufferers do no react to anxiety with predominantly cognitive or predominantly somatic symptoms. Rather, levels of both cognitive and somatic symptoms are raised above those reported by controls. This suggests that more general anxiety-reduction techniques may be most appropriate, such as the group counselling sessions reported by Price *et al* (1991), and helps explain why anxiety in their experimental group did indeed decline between sessions.

To summarise, psoriasis patients show higher levels of trait anxiety than controls, and levels of current anxiety when measured over the last week tend to change as area of coverage changes: the older the individual, the more the change. The ratio of cognitive to somatic symptoms reported in anxious situations is not different from controls, but psoriasis sufferers report *more* cognitive and somatic symptoms than controls, which

has been interpreted as a response stereotype. This is relatively resistant to change, since neither the ratio nor the absolute levels of cognitive and somatic anxiety changed between assessments.

6.4.4 **Self-Esteem**

Only one study had previously examined self-esteem in psoriasis sufferers, and then only indirectly through feelings of stigmatisation (Ginsburg & Link, 1989). Those authors found longer time since onset to be associated with lower scores on their *guilt* and *shame* subscales, but neither total area of coverage nor visibility of lesions was related to scores on their questionnaire. In the cross-sectional study reported here, it was hypothesised that global self-esteem in the psoriatic group would be lower than global self-esteem in the control group. This hypothesis was not supported: there was no significant difference on the global self-esteem measure between the two groups. Similarly, there were no differences on four of the five subscales: *contentment, worthiness and significance; competence, resilience and control; self-evaluation;* and *value of existence*. The only difference was on the *attractiveness* subscale, where females psoriatics scored higher than controls; yet this score was not related to any psoriasis-specific variable. In the second study, however, change in the global self-esteem score, the *competence, resilience and control* subscale, and the *attractiveness* and *value of existence* subscales was significantly predicted by change in area of coverage. The difference in magnitude of the regression line slopes between males and females may be another reflection of the lower range of area of coverage scores in females, but it is also possible that self-esteem was generally more stable in the females studied. The very large differences between slopes in all the above scales would tend to support this interpretation, particularly since the slopes for women were close to zero.

Self-esteem scores in the second study generally were higher than in the first, (higher than for both the psoriasis group and controls), suggesting that the group in the second study had quite elevated levels of self-esteem. This was contrary to expectations and requires some explanation. Most conceptions of self-esteem involve some sort of evaluation of interaction with other people (e.g. Cooley, 1956; Mead, 1934; Marsh, 1986; Robson, 1989). That is, self-esteem is acquired and maintained through interpretation of others' opinions, or through comparison with others' abilities. Individuals with stigmatising marks (e.g.psoriasis) experience negative reactions from others. In the case of psoriasis this was apparent in the study reported in Chapter 4 but also clearly present in other data, e.g. Jowett & Ryan, 1985; Savin 1970, and Ginsburg & Link (1989) have demonstrated that psoriasis sufferers feel part of a stigmatised group. In theory this should lead to lowered self-esteem.

However, there is considerable evidence that membership of a stigmatised group does not in itself lead to lowered self-esteem (e.g. Major, Carrington & Carnevale, 1984; Burden & Parrish, 1983). In explanation of this, Crocker & Major (1989) proposed that stigma may give rise to the development of self-protective strategies, which in turn will lead to *raised* self-esteem. Since this would in some part explain the findings of the two studies reported here it is worthwhile examining these hypothesised self-protective strategies in more detail. Crocker & Major examined three possible self-protective strategies, all of which may apply to psoriasis sufferers.

The first was attributing negative feedback to prejudice against the group or condition. Negative feedback, for example, revulsion reactions from the public, are attributed to prejudice or ignorance rather than accepting that the appearance of the condition may in reality be quite distressing to some people who are not used to seeing it. There is some evidence that psoriasis sufferers are aware of other peoples' reactions (e.g. Jobling, 1976; Stankler, 1981), but no research has attempted to ascertain what attributions sufferers make for these reactions: that is, whether it is attributed to prejudice against the condition. However, informal discussion with patients in the present studies (Chapter 4) suggested that psoriasis sufferers feel others' reactions are based on ignorance of the condition. This may be indicative of a self-protective strategy when in the presence of others, but may also lead to avoidance of situations where these reactions are likely to occur.

The second was selectively comparing outcomes with ingroup members. This strategy involves comparing what happens to you with what happens to other people with a similar stigma, rather than comparing with those without stigma. Thus, it can be hypothesised that psoriasis sufferers who employ self-protective strategies should identify more closely with other skin sufferers than with non-sufferers. This may have been reflected in the knowledge interviews where, when questioned about what other illnesses were in the same 'family' as psoriasis, out of 34 responses, 20 were of other skin diseases (see Table 4.7). It may also have been reflected in the over-estimations of prevalence of psoriasis.

The third was selectively devaluing attributes on which the group fares poorly and valuing attributes on which it fares well. This would suggest that as a self-protective strategy, psoriasis sufferers should devalue areas from which they are, or they feel, excluded, for example sports, sunbathing in public, swimming. It is certainly the case that psoriasis sufferers tend to avoid these activities (Jowett & Ryan, 1985; Dooley & Finlay, 1990).

Crocker & Major (1989) also propose certain factors moderating their hypothesised self-protective strategies.

The first is token (or solo) status of the sufferer, that is, whether there are many or few other people with the same stigma. This should result in initial lowering of self-esteem (Pettigrew & Martin 1987), and may in part explain the overrating of the prevalence of psoriasis found in the knowledge study. It can be hypothesised that inflating the number of sufferers operates as a self-protective strategy by diminishing the token status of the individual. The true prevalence in Britain is between 1 and 2%, but 60% of respondents estimated the prevalence to be over 10%.

Secondly, time since acquiring the stigmatising feature, Crocker and Major suggest, is important because it takes time to acquire self-protective strategies. However, this is not supported by the current data because self-esteem would be expected to vary with length of suffering, yet it does not.

These strategies, it should be stressed, are hypothetical, but the data collected in this research does fit their general framework, and it would be instructive in future research to examine self-protective strategies for self-esteem in psoriasis.

To summarise, in the first study there was no difference between psoriasis sufferers and controls on total self-esteem, and the only difference was on the *attractiveness* subscale, where female psoriatics rated themselves as *more* attractive than controls. In the second study, where psoriasis involvement was more widespread, self-esteem levels were generally raised. This may be because the psoriasis sufferers were employing strategies to protect their self esteem, and may in part explain some of the results of the patient knowledge interview. Some subscales of the self-esteem scale vary with area of cover-age, more so for men than for women.

6.4.5 **Sleep and Pain.**

While sleep disturbance is not generally examined in relation to psoriasis, two recent findings prompted its inclusion in the prospective study reported here. First, the Not-tingham Health Profile used in the cross-sectional study to examine perceived health status found a significant difference between psoriasis sufferers and controls on the sleep subscale, which assesses sleep disturbance. The NHP is a rather coarse measure and does not give any detailed information on the nature of sleep problems. These findings were supported in the patient knowledge interview, with 51% of respondents stating that they thought psoriasis affected the way people sleep, and indicating that

they thought this problem would be most apparent when the psoriasis was severe. Subsequent to that study, Finlay *et al* (1990) found psoriasis sufferers scoring considerably higher on the SIP sleep scale, which again measures sleep disturbance.

The results of the prospective investigation found psoriasis sufferers general sleep quality related to disease severity: that is, as psoriasis changed, so sleep quality changed, but this was found only as a general measure and was not reflected in any of the subscales.

The NHP subscale that measures pain also showed a difference between controls and psoriasis sufferers. This was interesting because pain is not generally thought to be a feature of cutaneous psoriasis. Since the NHP was not designed to assess pain in detail, the MPQ was used in the second study to examine the nature of this reported pain. The pain quality scales provided some useful information on the nature of pain associated with psoriasis, and suggests that psoriatic pain can best be described as *itchy, sore,* or *tender*, and *annoying*. These descriptions of pain quality tend to decline as the psoriasis improves, which suggests that pain and irritation qualitatively change with the state of the condition.

6.5 Significance of the regression models

In Chapter 5 psychological variables and disease severity in psoriasis were modelled by linear regression. A number of equations were generated which it was shown fitted the data well, with R^2 values ranging from 0.44 to 0.79. These equations are not just an exercise in statistical modelling: they offer real insight into the link between psoriasis and psychological variables. By using these models, it is now possible, with a high degree of confidence, to predict the likely effects of change in psoriasis severity on depression, anxiety, and self-esteem, and to predict also how sleep disturbance and the quality of pain will change as psoriasis progresses. At a practical level, this has implications for management of psoriasis patients.

Consider two hypothetical patients presenting with psoriasis assessed as moderately severe, say, 10% body coverage: one a male of 20 years, the other a female of 40, and both having developed psoriasis at the age of 12. Assume that both have the same levels of depression and anxiety (say, a score of 10 on the HADS) and a global self-esteem score of 130 on the SEQ. What effects might a change in area of coverage of 5% entail for each of these patients? Using these figures in the regression equations presented in Chapter 5, predictions made from that same change in area of coverage of 5% would be that for the man, self-esteem would be expected to rise to 164, anxiety fall to 6.6, and depression would be expected to fall to a HADS score of less than 1. For the woman, on

the other hand, self-esteem would only be expected to rise marginally to 136, anxiety fall from 10 to 8, and depression fall only to 8.6: a decrease of only just over 1 point on the HADS. Assume also relatively poor sleep quality (say a score of 10 on the PSQI). For the same change in area of coverage, the young man's score would drop to 6, but the older woman's score would be expected to fall only to a score of 9.

These are, of course, hypothetical figures and the models only *predict* changes in scores. The psychological state of each individual patient will be influenced by a variety of different factors which must also be taken into account. Domestic or employment problems, for example, could be expected to influence depression and anxiety scores, and sleep quality may vary for a number of reasons quite apart from psoriasis severity. However, given the high R^2 values, these predictions are likely to be quite accurate in a large number of cases, and could form the basis for formulating treatment regimens and guiding decisions about possible referral to psychiatric or psychological support agencies. Predictive models such as these can also be used to identify individuals who are not responding in ways that the models predict and can thus be useful for picking up people whose depression is getting worse, for example, while their psoriasis is getting better, so that appropriate further investigation can be initiated.

One immediate application is to the SKINMAP program developed as part of this research. As already noted, SKINMAP already has the facility to run external programs and combine the data collected with its own estimates of disease severity. Incorporating simple measures of depression, anxiety and self-esteem into the computer assessment procedure would allow the program to monitor disease progress and psychological state and, based on the linear models generated in Chapter 5, identify cases where further psychological assessment would be appropriate. This is not to suggest, of course, that clinical decisions about patient care should be compromised. Rather, it would offer an immediate assessment and permanent record of both the physical and psychological state of psoriasis sufferers, together with a preliminary evaluation of their interrelationships, upon which clinicians could choose to act appropriately.

To summarise, regression models have been fitted to the data collected from psoriasis sufferers over time, and allow prediction of levels of psychological variables with a high degree of confidence. Application of hypothetical case data to those models highlights the importance of sex and time since onset of psoriasis, as well as absolute area of coverage and change in area of coverage. These models will be incorporated as part of general extensions to the SKINMAP program.

6.6 Implications of the research findings for the treatment of psoriasis

While it has been quite well established that psoriasis sufferers hospitalised for their condition tend to have quite high levels of anxiety and depression, it has not until now been demonstrated that psoriasis out-patients also exhibit higher levels of depression and anxiety than a suitably matched control group of non-sufferers. The findings of this research show that higher levels of depression and anxiety *are* associated with relatively mild psoriasis and should be considered as part of the general treatment of the psoriasis patient. It should also be kept in mind that depression and anxiety fluctuate as the disease progresses, so regular monitoring should also be a feature of psoriasis management.

Sleep disturbance in psoriasis patients has not previously been examined in any detail and the monitoring of sleep quality has not been considered part of the therapy process. The results of this research have shown a generalised decline in sleep quality as the disease worsens, and those responsible for maintaining psoriasis patients should be aware that sleep quality and disease state tend to co-vary, so that appropriate assistance can be offered when required.

Apart from the measurement of pruritus in psoriasis, pain and discomfort are not usually considered major symptoms. This research has shown that the quality of pain experienced from psoriasis tends to change as the disease progresses, and the more widespread the psoriasis, the worse the pain-descriptor words used. Anti-histamines are sometimes prescribed for itch, but no real pain management strategies are taught or offered as part of psoriasis treatment. Careful monitoring of pain description by patients would identify times when pain starts to become a problem and allow intervention before pain rises to the "unbearable" level that was found in the present research.

Levels of knowledge about psoriasis were found to be quite high, but some gaps in patients' knowledge should be filled and some misconceptions rectified. Almost all the respondents to the interview described in Chapter 4 said they thought it would help them control their psoriasis if they knew more about the condition. This would seem to be particularly pertinent to knowledge about treatment, where respondents showed a high level of misunderstanding, evidenced both by 54% thinking that all treatments prescribed by doctors are really just different strengths of the same thing, and also by the number of respondents who incorrectly named treatments that they thought were "non-medical", which in fact were standard medical treatment options.

6.7 Conclusions

This thesis has been concerned with levels of depression, anxiety and self-esteem, with the evaluation of sleep quality and the qualitative investigation of pain associated with psoriasis, and with discovering the lay beliefs and knowledge about psoriasis in those who suffer from the condition. It has also involved developing and validating a new means of assessing psoriasis severity.

The most important conclusions are that psoriasis sufferers whose disease is not severe enough to warrant hospitalisation nevertheless experience psychological effects that do not afflict non-sufferers to the same degree. Furthermore, the extent of psychological disturbance is related to the area of the body covered by the disease, to the length of time the individual has had the disease and, most importantly, to the sex of the individual sufferer. This research has shown that change in psychological disturbance can be predicted by regression models, and thus enables clinicians to be more aware of those cases who may require psychological intervention.

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Appendix One

Area of Coverage Raw Data

TABLE A2.1. Area of coverage of psoriasis on transparencies of 10 subjects assessed by planimetry, and assessed by four clinicians (A, B, C & D) for three body areas. (From Marks *et al*, 1989)

	Trunk					Arm					Leg				
	Rater					*Rater*					*Rater*				
Subject	1	2	3	4	Plan	1	2	3	4	Plan	1	2	3	4	Plan
1	0	0	0	0	0	2	5	2	3	1.8	2	5	2	2	1.6
2	<1	5	2	3	0.4	3	10	4	4	1.9	2	5	3	2	1.2
3	21	50	12	16	14.6	12	30	5	12	12.1	0	0	0	0	0
4	70	80	60	65	69.0	50	55	25	50	35.0	35	45	10	28	21.9
5	14	25	6	11	7.9	0	0	0	0	0	16	30	12	18	17.3
6	5	20	6	5	4.9	0	0	0	0	0	0	0	0	0	0
7	6	10	1	4	1.1	3	15	2	5	1.5	9	20	3	7	4.9
8	4	10	2	3	0.9	6	20	5	7	5.9	25	25	6	10	10.2
9	40	50	25	30	34.5	40	40	30	30	30.4	15	10	9	10	24.8
10	7	15	5	8	7.2	5	15	7	13	9.5	4	10	3	5	5.0

Appendix Two

SKINMAP Operation

Procedure for using SKINMAP

Skin lesions are recorded by the observer (not the patient) by mapping them onto the body regions presented by SKINMAP. The program enforces a rigid order of operations and precludes progression to the next without satisfactory completion of the current operation.

1) Select DRAW from the main menu.
2) Basic demographic and personal information about the patient must be entered. Blank fields are not accepted.
3) Patches in SKINMAP are ellipses of variable size which, under normal operation, are moved around the screen with a mouse or using the cursor keys. The intial size of the patch is determined by the aspect ratio of the screen. Pressing the Escape key toggles the mouse (or cursor) movements between patch movement and patch size control. Vertical motion increases or decreases the vertical size, horizontal motion alters the horizontal size. Patches are fixed on the body region by pressing the left mouse button, or by pressing the Enter key on the keyboard, and irregular shaped lesions can be built up using multiple, overlapping patches.
4) Representations of seven body regions are presented successively, onto which patches are mapped using a mouse or the cursor keys (front and rear views of torso and arms, legs, and hands, and a front view of the head). The patient is asked to show each body region in turn as SKINMAP progresses through the displays and the observer locates a representation of each psoriasis patch on the screen.
5) For each region, once mapping has been completed, the observer is prompted to estimate reddening, thickening and scaling on three point scales.
6) Once all regions have been mapped, the data are saved to disk and the program exits.

Appendix Three

Interview Schedule

DECLARATION

It has been explained to me that everything I say in the course of this interview will remain strictly confidential.

I understand that the interview will be tape recorded, but that after the interview the tape will be transcribed, when any references that might identify me will be removed. Once transcribed, I understand that the tape will be wiped clean.

I give my permission for anything I say to be used for research purposes, in the knowledge that I shall not be identified personally in any way whatsoever.

Date: _____

Name: _____

Signature: _____

ID: ☐☐☐☐ Date: ☐☐☐☐☐☐

Thank you for agreeing to help us further with this research. I'd like to talk to you today about your thoughts and opinions of psoriasis, and if you have no objections, I'd prefer to tape our conversation. This is to make sure that I don't miss any of your ideas or misunderstand anything you say. Once I have transcribed the tape, and removed any references that would identify you, the tape will be wiped clean.

[TURN ON TAPE]

Although I **do** have a series of questions that I want to ask you, I **don't** want you to feel as though you should restrict yourself to short answers. I want to know what **you** think about psoriasis, so feel free to volunteer any information you think is appropriate.

Of course, anything you say to me is in the strictest confidence.

The first area that I'd like to look at is how widespread you think psoriasis might be, and I'd like to start by showing you some figures.

[GIVE CARD ONE]

1. What proportion of people in Britain would you estimate are currently suffering from psoriasis?

CARD ONE

0 Don't know

1 Less than 1 in 100.

2 About 2 in 100.

3 About 5 in 100.

4 About 10 in 100.

5 About 15 in 100.

6 About 20 in 100.

7 More than 20 in 100.

[TAKE BACK CARD ONE]

2. Do you think psoriasis affects equal numbers of men and women, or do you think one sex is affected in greater numbers than the other?

0 Don't know. **[Probe: No ideas at all?] GO TO Q.4**

1 Men and women are affected in about the same numbers. **GO TO Q.4**

2 More **men** are affected than women.

3 More **women** are affected than men.

3. Why do you think that is?

4. Do you think children are any more or less likely to develop psoriasis if one of their parents already has it?

0 Don't know. **[Probe: No ideas at all?] GO TO Q.6**

1 Children are MORE likely to develop psoriasis if one parent already has it. **GO TO Q.5(A)**

2 Children are LESS likely to develop psoriasis if one parent already has it. **GO TO Q.5(B)**

3 Children are neither more nor less likely to develop psoriasis if one parent already has it. **Go to Q.6**

5A. Can you tell me **why** you think children are MORE likely to get psoriasis if one parent has it?

5B. Can you tell me **why** you think children are LESS likely to get psoriasis if one parent has it?

6. Do you think there are any particular groups of people who get psoriasis more frequently than others?

0 Don't know. **[Probe: No ideas at all?] GO TO Q.8**

1 No. **GO TO Q.8**

2 Yes.

7. What groups?

8. Do you think psoriasis can be affected by how clean a person is?

   0 Don't know. **[Probe: No ideas at all?] GO TP Q.10**

   1 No. **GO TO Q.10**

   2 Yes.

9. In what way?

10. Do you think it's possible for psoriasis to be infectious - that is, under certain circumstances can someone else catch psoriasis from you?

    0 Don't know. **[Probe: No ideas at all?] GO TO Q.12**

    1 No. **GO TO Q.12**

    2 Yes.

11. Under what circumstances?

12. In people who already suffer from psoriasis, do you think it is sometimes possible for psoriasis to develop at the site of cuts or scratches?

    0 Don't know. **[Probe: No ideas at all?] GO TO Q.14**

    1 No. **GO TO Q.14**

    2 Yes.

13. Can you tell me why that should happen?

14. Do you think pregnancy can affect psoriasis at all?

    0 Don't know. **[Probe: No ideas at all?] GO TO Q.16**

    1 No. **GO TO Q.16**

    2 Yes: Makes it **worse.**

    3. Yes: makes it **better.**

15. Why do you think that is?

16. In general, do you think having psoriasis affects the way people sleep?

    0 Don't know. **[Probe: No ideas at all?] GO TO Q.18**

    1 No. **GO TO Q.18**

    2 Yes.

17. Why do you think that should be?

18. Can you tell me what actually happens to the skin in psoriasis?

    0 Don't know. **[Probe: No ideas at all?]**

    1 Skin cells grow too quickly.

    2 Other:

19. Do you think psoriasis may be an early form of any other disease?

    0 Don't know. **[Probe: No ideas at all?] GO TO Q.21**

    1 No. **GO TO Q.21**

    2 Yes.

20. What disease?

21. In your opinion, is psoriasis a member of a 'family' of illnesses.

    0 Don't know. **[Probe: No ideas at all?] GO TO Q.23**

    1 No. **GO TO Q.23**

    2 Yes.

22. What other illnesses would you put in the same family as psoriasis?

23. Once a person has psoriasis, do you think it is possible that it will ever clear away and not come back?

0 Don't know. **[Probe: No ideas at all?] GO TO Q.25**

1 No. **GO TO Q.25**

2 Yes.

24. Under what circumstances?

25. Are there any sorts of diet that are particularly good for psoriasis?

0 Don't know. **[Probe: No ideas at all?] GO TO Q.27**

1 No. **GO TO Q.27**

2 Yes.

26. What sort of diet?

27. Are all the ointments prescribed by the doctor for psoriasis really just different strengths of the same thing?

0 Don't know. **[Probe: No ideas at all?]**

1 No.

2 Yes.

28. I'd like you to try and name as many treatments as you can that you can get from a doctor or from the hospital for psoriasis? It doesn't matter whether or not you have used them personally.

TREATMENT	USED	EFFECTIVE
1. _____		
2. _____		
3. _____		
4. _____		
5. _____		
6. _____		
7. _____		
8. _____		
9. _____		
10. _____		
11. _____		
12. _____		

Now I'd like you to try and assess how effective you think those treatments might be. Please choose your answers from one of these options.

[GIVE CARD TWO]

Have you ever used <TREATMENT>?

0 Don't know

1 No

2 Yes

(Although you have never used <TREATMENT>), how effective do you think it is?.

CARD TWO

0 Don't know.

1 Doesn't work at all.

2 Works a little.

3 Works a moderate amount.

4 Works quite well.

5 Works very well.

29. Now I'd like you to try and name as many treatments as you can that you can **NOT** get from a doctor or from the hospital for psoriasis? Once again, it doesn't matter whether or not you have used them personally.

TREATMENT	USED	EFFECTIVE
1. _____	☐	☐
2. _____	☐	☐
3. _____	☐	☐
4. _____	☐	☐
5. _____	☐	☐
6. _____	☐	☐
7. _____	☐	☐
8. _____	☐	☐
9. _____	☐	☐
10. _____	☐	☐
11. _____	☐	☐
12. _____	☐	☐

Now I'd like you to try and assess how effective you think those treatments might be. Please choose your answers from one of these options.

[GIVE CARD TWO]

Have you ever used <TREATMENT>?

0 Don't know

1 No

2 Yes

(Although you have never used <TREATMENT>), how effective do you think it is?.

0 Don't know.

1 Doesn't work at all.

2 Works a little.

3 Works a moderate amount.

4 Works quite well.

5 Works very well.

[TAKE BACK CARD TWO. GIVE CARD THREE]

30. People find out about psoriasis from all sorts of places. Which of these sources do you think has provided you with most information about psoriasis? **[Probe: And which would be next? etc.]**

Doctors

Newspapers

Magazines

Television

Radio

Family and friends

Other psoriasis sufferers

[TAKE BACK CARD THREE]

31. Have you had any information about psoriasis from anywhere else?

32. Do you think it would help you to control your condition if you knew more about psoriasis?

0 Don't know.

1 No.

2 Yes.

33. Why do you think that is?

Appendix Four

SEQ Subscale Scores and NHP scores for Cross-Sectional Study

TABLE A3.1 Summary of SEQ subscale scores from cross-sectional study for matched samples (n=114) of psoriasis sufferers and controls

Sample	*Group*	*Mean*	*SD*	*Range*	*t*	*Sig*
Contentment, worthiness & Personal Significance						
All	Controls	3.9	1.3	1.6-6.4	-0.9	-
	Psoriasis	3.7	1.4	1.1-6.7		
Male	Controls	4.2	1.1	2.3-6.4	-0.4	-
	Psoriasis	4.1	1.2	1.4-6.6		
Female	Controls	3.7	1.4	1.6-6.3	-0.4	-
	Psoriasis	3.4	1.4	1.1-6.7		
Competence, resilience and control						
All	Controls	5.0	0.9	3.0-6.9	1.4	-
	Psoriasis	5.2	0.7	3.9-7.0		
Male	Controls	5.1	0.8	3.6-6.6	0.7	-
	Psoriasis	5.5	0.6	4.0-6.5		
Female	Controls	5.0	1.0	3.0-6.9	1.2	-
	Psoriasis	5.2	0.8	3.9-7.0		
Attractiveness						
All	Controls	4.8	1.1	2.4-6.6	1.5	-
	Psoriasis	5.1	0.8	3.9-7.0		
Male	Controls	5.2	1.0	3.4-6.6	-0.5	-
	Psoriasis	5.0	0.8	3.6-6.6		
Female	Controls	4.3	1.1	2.4-6.4	2.5	0.02
	Psoriasis	5.2	0.8	3.8-7.0		
Value of existence						
All	Controls	4.8	1.2	1.3-6.8	-0.2	-
	Psoriasis	4.8	1.2	1.8-6.7		
Male	Controls	4.7	1.1	2.2-6.3	1.3	-
	Psoriasis	5.1	1.0	2.8-6.7		
Female	Controls	4.9	1.3	1.3-6.8	-1.6	-
	Psoriasis	4.6	1.2	1.8-6.7		
Self evaluation						
All	Controls	5.0	1.4	1.5-7.0	-0.4	-
	Psoriasis	4.9	1.4	0.0-7.0		
Male	Controls	5.5	1.2	3.0-7.0	-0.9	-
	Psoriasis	5.2	1.3	2.0-7.0		
Female	Controls	4.7	1.4	1.5-7.0	0.0	-
	Psoriasis	4.7	1.4	0.0-7.0		

TABLE A3.2 Summary of NHP scale scores from cross-sectional study for matched samples (n=114) of psoriasis sufferers and controls

Scale	*Sample*	*Group*	*Median*	*SIR*
Energy	All	Psoriasis	0	12.0
		Controls	0	19.6
	Male	Psoriasis	0	12.0
		Control	0	6.0
	Female	Psoriasis	0	27.7
		Control	30.4	31.6
Pain	All	Psoriasis	0	6.9
		Controls	0	0
	Male	Psoriasis	0	2.5
		Control	0	0
	Female	Psoriasis	0	17.8
		Control	0	0
Sleep	All	Psoriasis	12.6	21.3
		Controls	0	6.0
	Male	Psoriasis	12.6	21.3
		Control	0	3.2
	Female	Psoriasis	6.3	22.5
		Control	0	6.3
Emotional Reactions	All	Psoriasis	9.8	10.5
		Controls	9.3	9.2
	Male	Psoriasis	0	8.5
		Control	0	6.7
	Female	Psoriasis	11.9	13.7
		Control	9.8	13.7
Social Isolation	All	Psoriasis	0	0
		Controls	0	0
	Male	Psoriasis	0	4.8
		Control	0	0
	Female	Psoriasis	0	0
		Control	0	10.0
Physical Mobility	All	Psoriasis	0	5.3
		Controls	0	2.6
	Male	Psoriasis	0	5.3
		Control	0	5.3
	Female	Psoriasis	0	5.4
		Control	0	0