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Only Skin Deep: Examining Vitiligo from a Biopsychosocial Perspective

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Thesis submitted in fulfilment of requirements for the degree of Doctor of Philosophy

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1998

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DECLARATION

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ACKNOWLEDGEMENTS

Many people have helped me to complete this study and I am very grateful to all of them. However, I would like to give special thanks to the following:

-*The vitiligo patients* who took part in the study

-*The Vitiligo Society* and in particular Maxine Whitton, Michael Wandsworth and Marion Lesage who were always their to provide support, information and encouragement

-*Professor Robert Bor and Dr. Charles Legg* for their invaluable guidance and expert direction. Thank you for reading and re-reading the numerous drafts of chapters and for patiently listening to my anxieties and concerns. You have taught me so much, this study could not have been completed without your help, thank you.

-*Dr. John Hawk and Dr. David Gawkrodger* who allowed me to approach their patients and provided feedback and information on the medical aspects of vitiligo

-*Malcolm Cross* for always listening, supporting, believing in me and for making me laugh, even at the most difficult of times.

-*My parents* from whom I have drawn support, strength, love and inspiration. Thank you for your encouragement, patience and unconditional love.

-*Theo,* my partner and best friend, thank you for always listening, and never looking bored even when I rambled on about the pitfalls of multivariate stats! Most of all thank you for being there whenever I needed you and for motivating me to carry on. I couldn't have done this without you *(2π)*.

Preface

The research outlined in this thesis stems from empirical work carried out with vitiligo sufferers over a period of 3 years, from 1995 to 1998. Vitiligo is a pigmentation disorder, which causes the destruction of melanocytes in the skin. The affected areas lose their pigmentation resulting in the appearance of irregular white patches over the surface of the skin. Although the appearance of the skin can change dramatically, vitiligo does not cause any pain or physical discomfort, nor is it in any way physically limiting. Therefore the psychological effects of the disfiguring nature of this condition can be studied independently of other physical changes.

The present research was prompted by the recognition that empirical studies in the field of psychodermatology are scarce, especially with regard to the effects of skin disease on psychological health. Vitiligo provides a unique opportunity to examine the psychological impact of disfigurement in the absence of other variables such as pain, or trauma. Furthermore, unlike other skin conditions, such as eczema and psoriasis, few empirical studies have been carried out to examine the impact of a patient's psychological state on the progression of vitiligo and therefore, an opportunity to undertake some preliminary research in this field was identified.

The main thesis of the research outlined herein is that mental state and physiological state are not independent of each other for vitiligo sufferers. A patient's psychological state may influence the onset or progression of their condition, and the appearance of the condition may impact upon a patient's psychosocial functioning. With this hypothesis in mind, a series of studies were undertaken, examining the interaction between mental and physiological state in vitiligo. Four central hypotheses were examined:

1. Newly diagnosed vitiligo patients experience a higher proportion of stressful life events in the year preceding the onset of their condition, than a matched clinical sample.

2. Psychological counselling using cognitive behaviour therapy helps to improve the body image, self esteem and quality of life of vitiligo patients and may impact upon the progression of their condition.

3. Being involved in a non-directive support group helps to improve the body image, self esteem and quality of life in vitiligo sufferers.

4. Variation exists across vitiligo sufferers regarding their beliefs about the onset, course and symptomatology of their condition. These beliefs will vary according to demographic variables.

It is anticipated that amongst others, the present study may be of interest to clinical and counselling psychologists and counsellors working in the field of disfigurement, dermatologists, nurses, general practitioners and other health professionals who have face-to-face contact with dermatology patients, and health and social psychologists involved in research in this field.

CHAPTER 1

THEORETICAL FRAMEWORK

1.1 Introduction

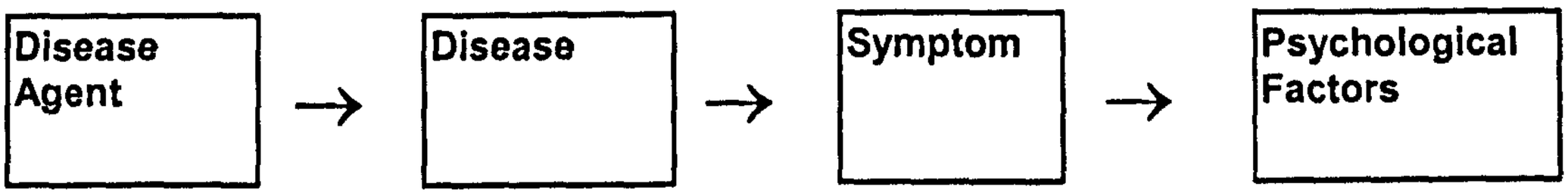
The skin has been referred to as the organ of expression (Sack, 1928). As the largest organ of the body it serves as the boundary between ourselves and the outside world. It acts as the surface of contact between us and our environment. It defines our limits and gives us insight into internal somatic and psychological processes. Its capacity to react to physical (e.g. developing a rash from a infectious substance) and psychological stimuli (e.g. blushing when shy or embarrassed) suggests that the skin is a complex organ which affects, and is affected by, both physical and psychological systems.

1.2 Limitations and Advantages of the Biomedical Model

Skin disease has predominantly been studied from a biomedical perspective, an approach founded on the belief that physical and mental aspects of health are separate and subject to only limited interaction independent of the disease process. This model takes a mechanistic view of the body, conceiving illness as an agent which disrupts normal

functioning, and defining health merely as the absence of disease (see figure 1).

Figure 1 Linear view of the disease process



By emphasising illness over health, the biomedical model focuses on anomalies that lead to illness rather than on conditions that may promote health. It is a reductionist theory, which ignores the complexity of factors involved in health and illness. It reduces illness to low-level processes, such as disordered cells and chemical imbalances, not recognising the role of more general social and psychological variables (Schwartz, 1982).

The biomedical model has historically dominated medicine, maintaining that illness can be explained in terms of aberrant somatic processes. It clearly assumes a mind-body dualism, maintaining that the two are independent entities (Engel, 1977). This is not to say however, that the biomedical model is not a useful framework within which to conceptualise disease. Indeed, the biomedical model has led to the development of many treatments, which destroy pathogens and ease pain. It has also been responsible for the development of vaccines to protect against viral disease, and advances in medical technology to diagnose disease.

Developments such as these were responsible for some of the greatest health advances in history. Hundreds of diseases caused by a variety of pathogens are now preventable or treatable following research based on the biomedical model.

1.3 Typology of Illness

Variation exists with regard to the course, outcome and duration of different illnesses. Some are brief and disrupt our lives only minimally, others take longer to run their course and others never entirely disappear, oscillating between periods of exacerbation and dormancy. A substantial body of literature suggests that these fluctuations are not necessarily due to biological influences but can be attributed to psychological and social factors. In cases where the illness worsens, factors such as anxiety, impaired social support, and traumatic life events have been cited as contributing to this deterioration (Spacapan and Oskamp, 1988). In cases where there is a stabilisation or improvement in the condition, factors such as strengthened social support, improved self esteem and enhanced self efficacy are thought to play a role (Kleinman, 1988). One study, which underscores this idea, was that of Berkman and Syme (1979). The authors gathered information regarding social support from 7000 residents of Almeda County in California and then tracked their mortality and morbidity rates over a nine year period. The results indicated that people who had

few social and community ties had significantly higher morbidity and mortality rates than those with strong social support systems. Indeed these results indicated that having strong social contacts enabled women and men to live on average 2.8 and 2.3 years longer respectively. Further, these effects were not found to be caused by differences in socio-economic status, health status or health habits.

Despite the advantages of the biomedical model, it is nonetheless incomplete. While it works well when applied to illnesses resulting from specific pathogens or infectious diseases, it is too restrictive to take into account the interplay between biological, psychological and social factors which relate to the cause, course and treatment of many conditions including skin disease (Jemott and Locke, 1984).

When the dry, pink lesions on one's skin for example, can be attributed to psoriasis and be successfully treated by a course of steroids, the biomedical model can be considered a success. However, when these patches only appear when a patient is under emotional stress, respond as well to steroids as they do to relaxation exercises, and are causing body image disturbances and in turn sexual difficulties between the patient and their partner, then this model fails.

In the biomedical model psoriasis is considered to be a "common genetically determined disease of the skin consisting of well defined pink or

dull red lesions surmounted by a characteristic scaling." (Whitlock, 1976 pp127). In the biopsychosocial model it is a dynamic interplay between physiological processes (endocrinological imbalances), psychological states (anxiety, reduced self-esteem), and social situations (feeling embarrassed about lesions, believing that one is too unattractive to be touched).

Thus, from a biomedical perspective something essential to the experience of skin disease is lost. The psychosocial effects of skin disease are not acknowledged as a topic for clinical concern, and so do not receive an intervention.

Treatments which are assessed exclusively through improvement of the disease process are clearly insufficient in certain cases, suggesting that a system which incorporates psychological and social aspects of health and illness, a 'biopsychosocial' system, is needed (Engel, 1977). Such a system will have properties not accounted for by a simple linear model.

As Engel (1977) states: "a medical model must take into account the patient, the social context in which he lives and the complementary system devised by society to deal with the disruptive effects of illness" (pp.132).

1.4 Emergence of the Biopsychosocial Approach

The biopsychosocial approach was born out of the need to address the changing pattern of illness. At the beginning of this century many of the leading causes of death were contagious diseases such as tuberculosis or typhoid fever. By the 1950's however, the incidence of contagious diseases had declined dramatically and non-contagious diseases linked to life style such as lung cancer and heart disease were rising. Today, the majority of the leading causes of death in Western societies can be attributed to lifestyle factors (Department of Health and Human Services, 1992).

Several factors contributed to this change in illness patterns, one of the most important of which was the contribution of the biomedical model which led to the development of vaccines, better hygiene and improved medical treatment. Due to these advances, people were living longer and therefore the effects of the health compromising behaviours such as smoking and poor diet, were manifesting in the form of non-contagious diseases such as heart disease, cancer and stroke. The realisation that 'controllable' life style patterns and behaviours were to some extent responsible for many of the illnesses facing society led those working in the

field of health care and health promotion to examine illness from a biopsychosocial perspective.

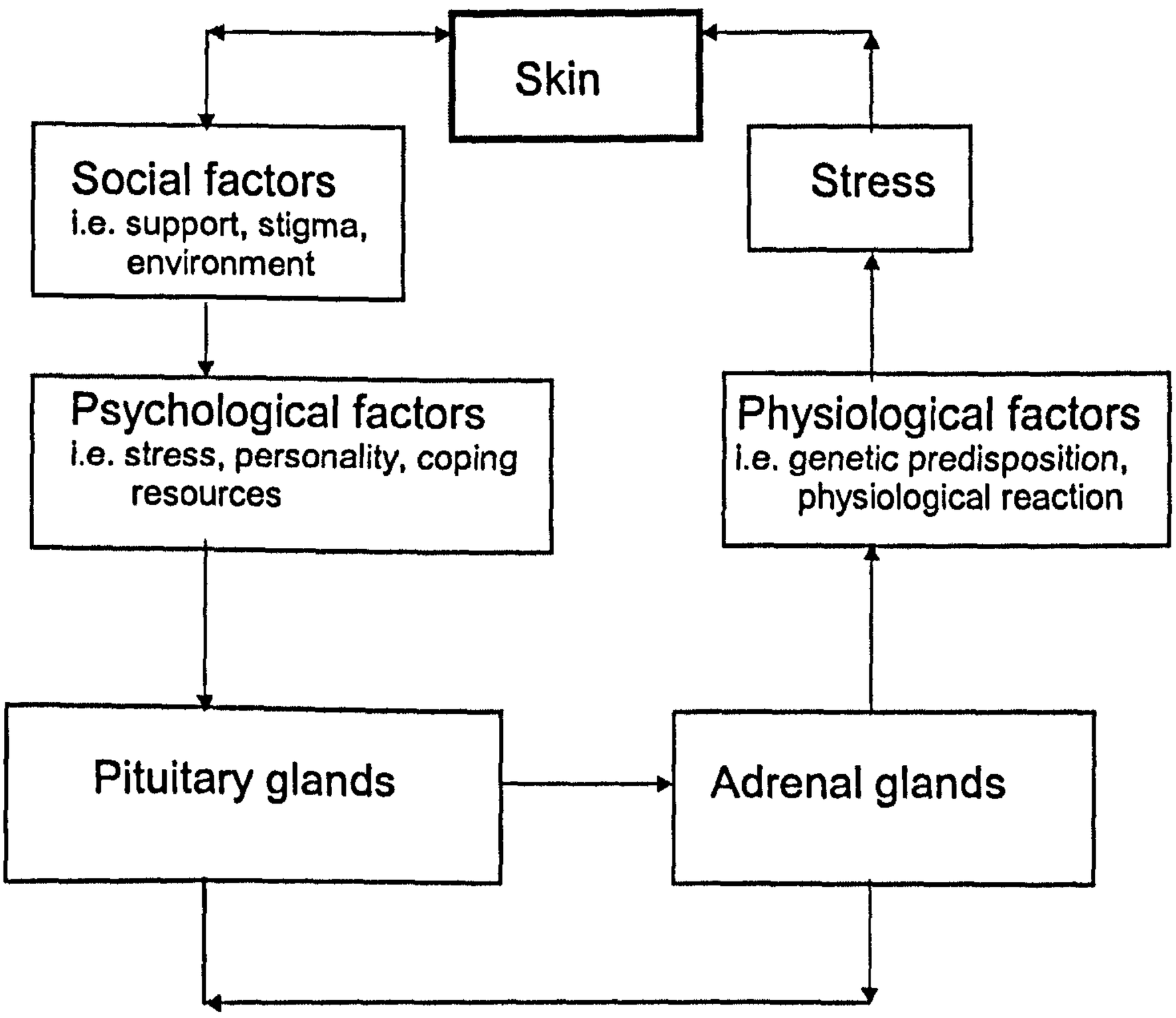
The biopsychosocial model of health and illness takes into account both macro-level process, such as social support and psychological stress, as well as micro-level processes such as cellular disorders or the presence of viruses, thus acknowledging that health and illness are caused by a variety of factors and produce a variety of effects. Indeed, it maintains that body and mind can not be separated in relation to health since both influence a person's health status (Knowles, 1977).

1.5 Systems Theory and the Biopsychosocial Model

The biopsychosocial model is based on general systems theory and acknowledges the interdependent, hierarchical relationships of biological, social and psychological systems. It underscores the fact that multiple systems interact simultaneously to bring about conditions of health and illness. A system can be defined as a group of interacting or interdependent elements that form a unified whole (Von Bertalanffy, 1974). The systems approach maintains that levels of organisation within a system are linked and that change in any one level will affect change in others. Thus, micro-level processes are nested within macro-level processes and change dynamically in relation to each other. The

biopsychosocial systems approach implies a perspective that differs from taking biological, psychological and social factors into account separately when considering illness. The biopsychosocial approach is a systems approach, in which the system has emergent properties not predictable from the properties of the separate elements (see figure 2).

Figure 2. A Systems Perspective of the Biopsychosocial Model In Cutaneous Disease



Health, illness and health care are therefore interrelated. Health is recognised as being partly dependent on internal systems such as the successful functioning at the cellular or organ level and partly dependent on external systems in the family and larger community. Eczema for example requires attention at the organ level but most dermatologists would agree that stressful environments and psychological states such as anxiety or depression, will affect the progression of the condition (Ginsburg and Link, 1989). Consequently, patient care requires interdisciplinary thinking and collaborative relationships (Schwartz, 1982).

1.6 The Psychosocial Emphasis

Skin disease is rarely just a personal and private matter. Unlike other less prominent conditions, skin conditions may be immediately visible to others thus denying the sufferer the choice of whether or not to disclose their illness experience to those around them. Consequently, patients are open to the disapproving reactions of friends and strangers alike, and such reactions have been found to evoke feelings of inferiority, stress or even reduced self esteem in patients (Porter, Beuf, Lerner and Nordland, 1992; Porter and Beuf, 1994).

Individual variation exists with regard to adjustment to visible skin disease. Although some people cope well with their condition others can become

very depressed and anxious about it (Porter and Beuf, 1994). Interestingly, these differences are not simply a product of the severity of the condition but rather, they are the result of an interaction of variables including social support, social skills, optimism, perceptions of self efficacy and coping style. (Lazarus, 1984; Kleber and Brom, 1992; Rumsey, Bull and Gahagen, 1986; MacGregor, 1990).

Although many people with skin disease cope effectively with the challenges of their condition, there exists a proportion of this population who find it difficult to face and cope with negative social reactions. It has been suggested that the disapproving reactions of people which dermatology patients come in contact with, may predispose them to stress and anxiety, and in turn, negatively influence the physical progression of various skin conditions (Teshima, Kubo, Kohara, Imada, Ago, and Ikemi 1982; 1986; Le Poole, Das and van der Wijngaard, 1993a). This in turn may compound the psychosocial effect of the condition, thus setting up a cycle whereby skin disease negatively affects psychosocial functioning and negative psychosocial experiences affect the progression of skin disease (See chapter 4).

In order therefore to understand the experience of cutaneous illness and to treat it effectively, there is a need to view the patient holistically, and to address the reciprocity between body and mind in relation to cutaneous

disease, in other words, to conceptualise skin disease from a biopsychosocial perspective.

A 'systemic' view of the dermatology patient began to emerge in the late 19th and early 20th century with the works of dermatologists like Beard (1880), Tuke (1884), Bukley (1906) and Winkler (1911). During this period however, although emotional and nervous disorders began to be cited as contributory causes of skin disease, researchers relied on anecdotal evidence of single cases to support their hypotheses. A very small proportion of authors mentioned specific psychological conflicts as potential causes of these conditions, (apart from the growing opinion that in women anogenital pruritus had something to do with sexual pathology!) (Whitlock, 1976). Conditions of unknown aetiology such as alopeicia areata and leukoderma tended to be associated with local "weakness" of the nerves. The emphasis on disordered neural rather than psychological functioning clearly dominated thinking during this period.

Beginning in the mid 1940's, more systematic studies on cutaneous illness began to originate. Stokes (1945) examined the personality dimensions of patients, with a variety of disorders in relation to 'psychoneurogenous phenomena' (a term he coined), including urticaria, rasacea and atopic dermatitis. However, as was the case with much of research in this period, a lack of adequate controls in these studies meant that few meaningful data were generated from this work.

Alexander and French and Pollock (1968) and Alexander (1950), were some of the first researchers to seek out specific emotional conflicts as the basis for psychosomatic conditions. Macalpine (1958) drew on this work in an endeavour to find a personality pattern for conditions like dermatitis and alopecia areata. Her attempts at identifying personality traits failed however, and in more recent years this type of investigation has been abandoned in favour of methods which employ psychometric tests for examining current functioning and coping style (Finlay and Khan, 1992).

Today, most researchers accept that looking for a single cause of skin disease is not useful, and that a multifactorial approach to psychocutaneous research is needed in order to fully understand the complexities of various skin conditions.

1.7 The Biological Emphasis

In order to apply the biopsychosocial framework to a comprehensive understanding of skin disease, there is a need to identify the physiological systems at the centre of this model. The study of *psychophysiology* affords a means through which the fundamental principles of the biopsychosocial model can be studied in a practical way. It provides a useful backdrop upon which to construct an understanding of the

mechanisms implicated in skin disease. It is concerned with cognitive, emotional and behavioural phenomena as revealed through physiological manifestations. Like the biopsychosocial model it provides a conceptual perspective and a methodological archetype that cuts across aspects of the biological, behavioural and social sciences.

Fundamental to the conceptualisation of psychophysiology is the basic assumption that human perception, thought, emotion and action are embodied phenomena. It is concerned not with isolated components of the body, but rather with transactions between organisms and their physical and psychosocial environments.

There are several theories which postulate psychophysiological mechanisms underlying various cutaneous diseases (Whitlock, 1976; Teshima et al., 1982; Root, Kent and Al' Abadie, 1994; Salzer and Scheullreuter, 1995). In order to understand how the skin can be conceptualised from this perspective however, some general points regarding psychocutaneous physiology need to be outlined:

Firstly, both the skin and the central nervous system develop embryologically out of the ectoderm. The central nervous system (CNS) derives from a specialised portion of the ectoderm known as the neural plate. Thus theoretically, if the two share their embryonic origin then they may be further connected in terms of their functioning.

Secondly, both the skin cells and certain nerve cells metabolise the amino acid tyrosine to produce either melanin or catecholamines respectively. Tyrosine metabolises into dopa → dopamine → noradrenaline → and finally adrenaline; alternatively it metabolises into dopa quinone → hydroxyindole → indole quinone → and finally melanin. It has been suggested that translation errors during this process may account for some of the acquired hypomelanotic disorders commonly observed, including vitiligo (Ortonne et al., 1983; Lerner, 1974). It remains unclear however, at which stage this metabolic error might occur, and indeed what the implications would be for central nervous system activity following such a metabolic translation error. One would expect, for example, that if the discoloration in vitiliginous skin was caused by this process then there would be some form of CNS disturbance, since a problem in the metabolisis of tyrosine would have the potential to affect not only melanin but adrenaline as well.

Thirdly, we know that apart from the dermal melanocytes, melanin producing cells exist in other parts of the body, for example melanin is present in the brain in the substantia nigra (Jarett, 1974). The fact that melanin is present in the brain prompts the suggestion that it might have biological functions other than photo-protection. Indeed, it has been shown that both naturally occurring and drug induced dyskinesia occurs only in species which posses melanin in the substantia nigra (Cotzias, 1964)

suggesting that melanin may have a more fundamental biological role than that of providing visible pigment. Further, the substantia nigra produces dopamine and melanin may be a by-product of dopamine production (see above).

There are three main disorders of melanin metabolism:

1) *Phenylketonuria*, in which pigment formation is affected through the reduction of phenylalaline hydroxylase activity, and thus the production of phenylalalnine to tyrosine proceeds at approximately 10% of the normal rate. This condition inherited as a recessive trait is characterised by decreased pigmentation in hair and eyes and if left untreated becomes associated with mental deficiency (Jervis, 1977).

2) *Albinism* in which there appears to be an abnormality in the tyrosinase, this is due to a genetic defect where tyrosine is in an inactive form causing ocular disturbances which are not solely associated with photosensitivity, and may have a neurological basis (Kaas and Guillery, 1973).

3) *The formation of toxic substances by tyrosinase* which interfere with melanocytic function. It remains unclear however, why pigmentory disorders like vitiligo, which are believed to have a neurogenic component in their aetiology, are not associated with any other type of physical

disturbance or indeed any type of symptom other than depigmentation, which can be seen in conditions such as those described above. Perhaps the neurogenic component of vitiligo is displayed in the formation of lesions which tend to conform to a segmental distribution of the peripheral nerves rather than in its direct affect on neurological functioning, as evidenced by clinical findings (Lerner, 1959a; Ortonne et al., 1983; Le Poole, 1997).

Finally, there also appears to be a relationship between the skin and the immune system. Both serve the same function, but in different ways, by protecting the body from infection. Clinical studies have shown that psychological stress can cause the suppression of Killer T-cells and macrophages, both of which have been shown to play important roles in skin related immune reactions (Teshima et al., 1982), these studies are described in detail in chapters 3 and 4.

Each of these theories underscores the fact that cutaneous illness is by no means a unidimensional physiological occurrence. Rather it is the product of an interplay between various complex systems including those of a psychosocial nature, many of which we have yet to fully understand. The concepts of cutaneous physiology will allow us to develop our thinking about skin disease in terms of how each of these systems interact and how an understanding of this interaction can be used to benefit patients.

1.8 The Diathesis-Stress Paradigm

Emotional factors have been linked to a wide variety of conditions ranging from cancer to heart disease (Altschuler, 1997), this raises an interesting question, namely, why do some people develop one form of disease in the presence of psychosocial stress while others develop something totally different? In order to understand this, we have to take into account physiological systems, not only as they interact with environmental and psychological variables, but in terms of their predisposition to a particular disorder. That is, acknowledging that biopsychosocial elements interact to bring about disease not at random but rather, in organs that are vulnerable or predisposed to certain conditions.

A paradigm which resonates with the biopsychosocial framework is known as the diathesis stress paradigm (Meehl, 1962). It focuses on the interaction between a predisposition towards disease (the diathesis) and environmental disturbances (stress). Although the term 'diathesis' tends to refer to a predisposition towards an illness, the term may be extended to any characteristic of the person that increases his or her chance of developing a disorder.

At a biological level, many diseases are genetically transmitted, therefore having a close relative with a disorder and sharing their genetic make-up to some extent, might increase the risk for a particular disorder. On a psychological level, a person's cognitive set, the way he/she perceives the world, may predispose them to certain illnesses, for example a chronic feeling of hopelessness may predispose an individual for developing depression.

Although possessing a diathesis for a disorder might increase a person's chances of developing it, it does not necessarily guarantee that the disorder will develop. The *stress* part of the paradigm, accounts for how the diathesis is translated into a disorder. It refers to stressful psychological or biological environmental stimuli. Examples of this can include poor nutrition or oxygen deprivation at birth, or traumatic life events such as loss of employment or bereavement (Meehl, 1962).

Adler's (1907) concept of organ inferiority resonates with this idea: "*Genetic factors are important determinants of the predisposition to certain diseases, for without this contribution one would have to assume that the choice of target organ was purely arbitrary*" (cf. Whitlock, 1976, pp18). Thus in the case of cutaneous illness the skin might represent the *weak organ*, so that emotional and psychological disturbances are expressed through manifestations of cutaneous disease (Ginsburg and Link, 1989).

In their research on relaxation therapies, in the treatment of psoriasis for example, Winchell and Watts (1988) suggest that individuals inherit or acquire a basic organ inferiority that will determine the results of psychological/emotional upsets so that autonomic activity may be directed towards the weak organ. The biopsychosocial view of the dermatology patient can allow one to postulate about acquired or genetic predispositions to illness, thus offering an explanation for why the same noxious external stimulus can precipitate skin disease in one person and something completely different in another.

The impact of *stress* (as indicated by the diathesis-stress model) is a personal, subjective experience that will affect people to varying degrees depending upon their perception of how unpleasant a particular stressor is, and the coping mechanisms that they have in place to cope with it.

Drawing from the discussion so far we can make certain predictions regarding the systemic nature of vitiligo. Firstly, it is likely that the disease process will be affected by psychological factors and the disease itself will impact upon psychological/emotional state. Secondly, psychological reactions to disease will be mediated by beliefs about the disease. Thirdly, the relationship between beliefs and disease is to some extent reciprocal; beliefs affect how we react to disease, and disease affects the beliefs we hold. The studies described in the thesis will attempt to examine these

hypotheses by using cultural differences to explore the impact of prior beliefs on the interpretation of disease and by using therapeutic techniques to manipulate beliefs.

1.9 Health Beliefs

How we interpret the social reactions we encounter from others is largely through the beliefs we hold about our world in general. Beliefs colour the way we perceive our surroundings; they dictate our behaviour and provide the foundations upon which we build our lives and interact with those around us. Beliefs about health and illness, guide our interpretations of treatment, cause and cure. They frequently relate to coping with uncertainty about the course of an illness, its outcome and the effectiveness of treatment. Illness beliefs serve as maps which we use to construct meanings about illness and direct decisions about treatment compliance and medical care.

There are numerous examples in the literature which show that beliefs about one's illness affect treatment compliance (Kirscht, Kirscht and Rosenstock, 1981; Becker and Janz, 1987), coping with illness, (Taylor and Clark, 1986) and in some cases affected the course of the illness itself (Kleinman, 1988). There is also evidence to suggest that through examining the beliefs and significance of a person's illness, it is possible to

break the vicious cycle proposed by the biopsychosocial model whereby psychosocial functioning affects physiological functioning and vice-versa (Kleinman, 1988).

The importance of health beliefs was recently underscored by Weiss et al. (1992) in his comprehensive work on leprosy, where he elicited the illness beliefs of a group of leprosy sufferers. He found that patients' beliefs were significant indicators of treatment compliance and indeed how they coped with, and adapted to, their condition. Thus, gaining an understanding of patients beliefs can help to guide the treatment and care offered to them.

Within the field of health beliefs, the Health Belief Model (Hochbaum, 1958; Rosenstock, 1966) is one of the oldest and the most frequently cited approaches (Becker, 1984). The Health Belief Model states that whether or not a person practices a particular health behaviour will depend on the degree to which they perceive a personal health threat and the belief that a particular health practice will be effective in reducing the threat. Factors such as health values, beliefs about vulnerability to a particular illness and the consequences of the disease, will influence one's perception of personal health threat.

If someone therefore believes that their eczema is exacerbated when they become stressed, they may try and minimise stress or engage in relaxation exercises. Similarly, if a person believes that their diet affects their acne

they may avoid certain foods. However, the decision to undertake certain health behaviours is also influenced by the extent to which the cost of undertaking that behaviour exceeds the benefits of doing so. If, for example, a person feels that undertaking relaxation exercises is one of the factors that improves their eczema but believes that reducing stress alone will not have a significant enough effect, then they may decide that the effort of doing the exercises will not be worth the benefits.

Although this model is able to identify different health beliefs, which sometimes help to predict different types of health behaviours, it has not been entirely successful as an explanatory model. It has been criticised for explaining the health behaviour only for those who have the funds and access to health services (Wolinsky, 1978). It has also been criticised on the basis that it can only predict the health behaviours of those who are familiar with their condition and the appropriate treatment for it (Weisenberg et al., 1980). The Health Belief Model fails to take into account the fact that factors, other than health beliefs, influence health behaviours. Cultural factors, previous experience with illnesses and social pressures all influence the practice of health behaviours.

The Health Belief Model has failed to show consistent predictive power of beliefs in relation to behaviour (Bennett, Weinman and Spurgeon, 1990). As a result, other models have sought to identify variables which contribute to the equation such as the Theory of Reasoned Action (Ajzen and

Fishbein, 1980) and its extension The Theory of Planned Behaviour (Ajzen, 1985), which highlight variables such as personal and peer group beliefs about different health behaviours. The Protection Motivation Theory (Rogers, 1983), adds the concept of self efficacy-expectancy to the HBM in an attempt to improve the explanatory power of health beliefs.

Although these models attempt to explain health related behaviours in terms of beliefs, one of the most powerful predictors of a person's future behaviour is their past behaviour. This suggests that it may be valuable to examine cognitive processes, which are used by the individual to make sense of past experiences. Drawing from this, some theorists working in the field of health psychology have proposed that the way in which health beliefs develop is through the generation of common sense representations of illness in order to integrate and organise information about symptoms of illnesses. People generate hypothesis about the nature of their problem and then search for information to confirm their hypothesis (Leventhal, Meyer and Nerenz, 1980; Bauman, Cameron, Zimmerman and Leventhall, 1989; Lau, Bernard and Hartman, 1983). These cognitive representations have 5 elements:

1. Identity: a label, either verbal or abstract placed on a set of symptoms

The identity of a disease is very important to illness behaviour. A woman who identifies the hyper-pigmented mark on her arm as a mole, may react

very differently to someone who identifies it as skin cancer. Thus, the presence of symptoms may not be enough to initiate help seeking, but this coupled with labelling may be a critical factor. It is of course less emotionally arousing to select a label that suggests a minor condition. As Lau and Hartman (1983) suggest, the strategy that people use in labelling illness comes from experience, since people tend to have few serious illnesses in their lives then it makes sense that their initial labels reflect common, minor conditions.

2. Time-line: beliefs about the course of the illness, whether it is chronic or acute

Although the course of illness is usually implicit within its diagnosis, patients' understanding of this is not always accurate. A study conducted by Meyer et al (1985) suggested that over 40% of recently diagnosed patients who suffered with hypertension (a chronic condition) tended to conceptualise their condition as acute, that is, they expected the onset of their symptoms to be followed by treatment, remission and eventually a cure. Interestingly among those patients who had lived with the condition for longer periods, only 12% retained the belief that their condition was acute, suggesting that if the time course does not support the patient's expectations about their condition, then re-labelling occurs.

3. Consequences: short and long term illness effects

Again, the consequences of a disease tend to be implied by the diagnosis. An incorrect understanding of the consequences however, can significantly affect health related behaviours. People who believe that the diagnosis of cancer is inevitably a death sentence, may not bother to seek medical treatment because they believe that their situation is hopeless. Stillman (1985) has suggested that women who find a lump in their breast avoid seeking medical help not because they fail to recognise the symptom as cancer, but because they believe themselves to be in a hopeless situation.

4. Cause: beliefs about what instigated the condition

The attribution of causality in symptoms is an important part of illness behaviour. Attributions are concerned with the way in which people explain events (Kelly and Michela, 1980), and how they use past experiences to infer causes in the present. For example, a person is more likely to attribute the discoloration on their skin to a post inflammatory reaction following a scratch or cut (something which they have had experience of in the past), then to think of vitiligo (which is not a common illness and has an unknown aetiology) as a possible cause of their depigmentation. They will also react very differently depending on what they attribute the cause to. Taylor (1983) suggests that the search for causal attributions is part of the process of coping with the illness. She indicates that this is particularly a

problem where the illness does not have a known cause (i.e. cancer, vitiligo) and that patients arrive at causal explanations even though these do not necessarily concur with medical science.

5. Cure: what the person feels they need to do in order to recover

The final component is to some extent related to cause. If for example a patient feels that eating greasy foods caused their acne, then they may in turn believe that an avoidance of greasy foods will cure it. This has strong implications for diagnosis and treatment, therefore if a patient doesn't agree with the proposed 'cause' or diagnosis then they will be less likely to believe in, and in turn adhere to, the proposed treatment (Taylor, 1983). However, the connection between cause and control may not be that simple, Marteau (1989) has noted that the distinction between perceived control over events and the attribution of causes of past events has been demonstrated in certain studies (i.e. Brickman et al., 1982). And therefore it is possible that attributions concerning the origins of an illness will not always, necessarily, be the same as those concerning its course.

It has been found that the way people 'represent' their illness affects the health behaviours that they engage in. For example, Leventhal et al. (1986) found that cancer patients who viewed their illness as curable and acute rather than chronic, tended to supplement their chemotherapy with others forms of treatment. Research in this area has also suggested that people

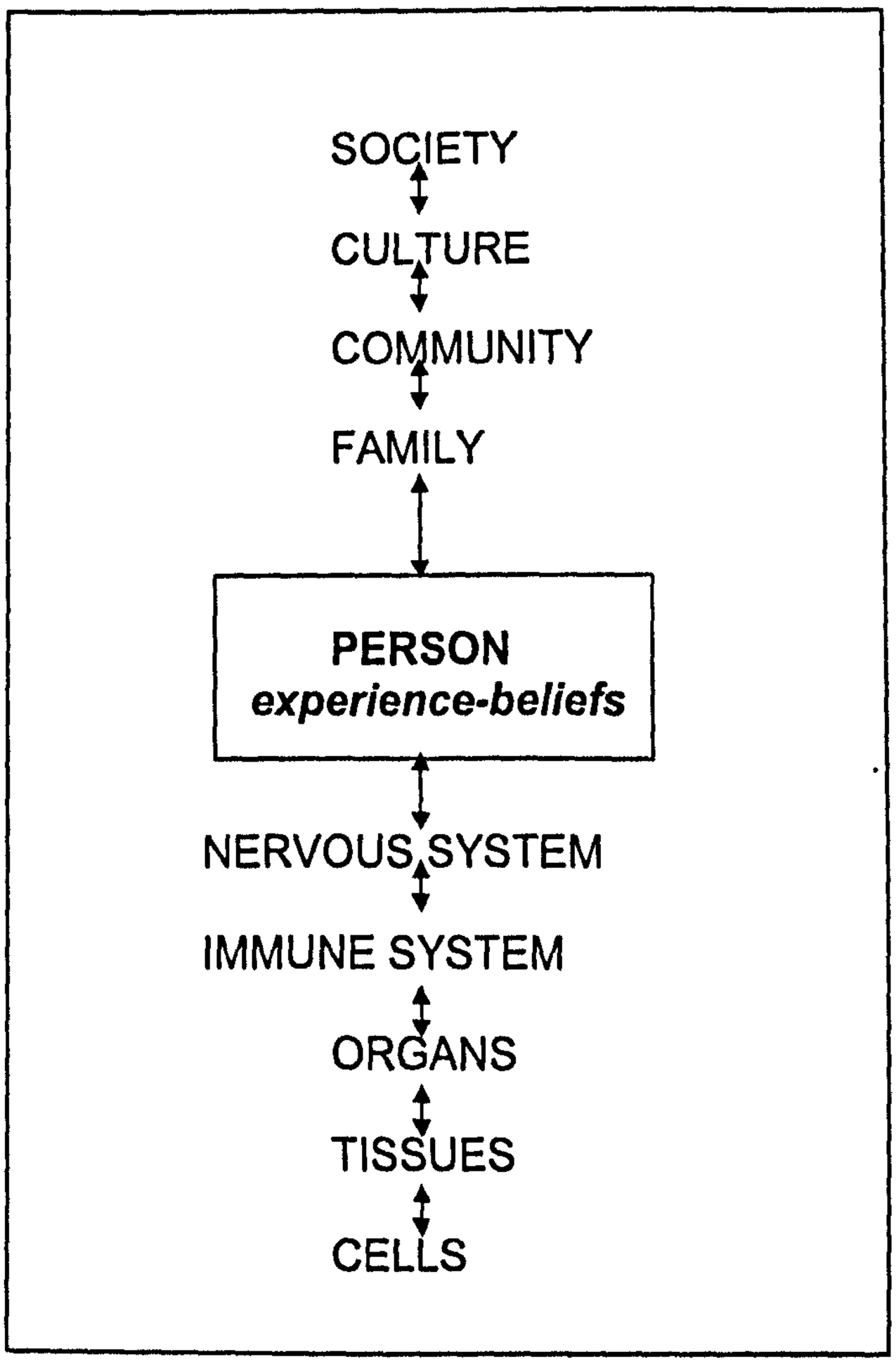
are more likely to visit their physician if they have strong cognitive representations of 'identity' (what the illness is) and 'cure' (how to recover) (Lau, Bernard and Hartman, 1989).

The concepts outlined above address how we interpret symptoms and signs of illness. However cultural differences may greatly affect these interpretations. A classic study by Zola (1966) found that the way that people present or react to physical complaints varied greatly according to culture. The author studied 144 patients of Italian and Irish decent who attended an eye and ear outpatient clinic. He found that Irish patients understated the severity of their symptoms, denying pain, whereas Italians were more dramatic in their descriptions and tended to describe a variety of symptoms related to several body parts. Such differences are also found in relation to social class, age and gender (Cleary et al., 1982; Cash, 1990).

The above discussion suggests that cognitions have the capacity to affect various health-related behaviours. However they may also influence a person's health directly through their impact on the body. The way that a person explains causal events has been found to be associated with both short-term and long-term health (Levy and Wise, 1987; and McClleland 1979). Cognitive factors which underlay coping mechanisms have been found to moderate the relationship between stress and immune system changes (Broome, 1989). In a study that examined the ability of

attributional style to predict physical illness, Peterson (1986) asked a sample of 176 students to complete a version of the Attributional Style Questionnaire. They found that physical illness could be predicted from attributional dimensions of stability and globality. Results of a more recent study (Kamen and Seligman, 1990) suggest that explaining causes of bad events and illness in terms of global, internal and stable factors was reliably associated with poor health in middle and late adulthood. The relationship between beliefs and physical illness has been further underscored by research suggesting that changing people's beliefs about the causes of events, and increasing their sense of responsibility and control, enhances immune functioning (Kiecolt-Glaser et al., 1985) and improves general health (Rodin and Langer, 1977). This suggests therefore, that there is a need to examine and understand patients cognitive representations, and how these originate since they have the capacity to affect an individual and their illness experience at several levels (See Figure 3).

Figure 3: Beliefs and the Systems Hierarchy



If we are to adopt a biopsychosocial perspective, which suggests that patients' health can be affected by psychological and social variables, then it is important to address how these will vary according to the beliefs patients hold.

In theory, if an illness is correctly labelled, then its course, consequences and outcome should be clearly understood by the patient. However, the literature reviewed above suggests that this is not always the case. Not all patients are well informed about their illness or condition. Furthermore, even when they have detailed information about their illness, lay beliefs and stereotypes may emerge that compete with the so-called medical model explanation. This will inevitably have implications not only on the way patients perceive their illness and adhere to treatment, but also on how they adjust to and accept their condition. Further, the literature above suggests that health beliefs can have a direct affect on physical health, underscoring the importance of these beliefs from a biopsychosocial perspective.

Many of the health belief theories described in the health psychology literature are intended to be applied to situations where the nature of the medical condition is understood, but some people do not carry out the appropriate health behaviours. The problem with conditions such as vitiligo, is that there is a lack of a clear aetiology or treatment for the disease. Therefore, before people can make decisions about their health behaviours, they need to develop an understanding of the nature of their problem. This means that before we can apply models that predict health behaviours we need find out how patients conceptualise their disorder, what their 'cognitive representations' of their illness are. The Cognitive

Representation Theory of illness (Leventhall et al., 1980; Lau et al., 1983; Bauman et al., 1989) provides the most useful theoretical construct on which to underpin such research. This theory allows us to examine how patients conceptualise their illness and to make predictions about how these concepts evolve and develop. This is particularly important from a counselling perspective where patient's beliefs about their condition can significantly affect their psychosocial adjustment to it (Weiss, 1988; Kleinman, 1988). In a recent publication by Petrie and Weinman (1997), the authors argue that cognitive interventions designed to challenge illness representations, can impact positvely on coping. They suggest that cognitive, emotional and behavioural responses to illness can both influence and be influenced by a person's self-concept. Therefore illness can have a significant effect on both self-concept and self-esteem. Similarly one's interpretation of their illness, and in turn how they cope with it, will be affected by variables such as personality, age and culture. Indeed, Landrine and Klonff (1992) stress the importance of understanding illness representations *within* the social and cultural contexts in which they occur.

Understanding a person's *understanding* of their condition will allow counsellors firstly to empathise with a patient's illness experience and secondly to work on challenging cognitive representations that are negative or irrational. Unlike the HBM, using cognitive illness representations to examine how the patient interprets their illness allows one to take into

account significant factors such as cultural influences and past experience. Since the studies described in this thesis are not concerned with predicting health behaviours, but rather with finding out how patients conceptualise their disease, and in turn how they react to it psychologically, it is important that the model which underpins the research takes into account the cognitive representations of patients.

By underpinning our research with the biopsychosocial model and the complimentary model of cognitive illness representations we are making certain assumptions:

1. People are not passive responders rather they are active problem solvers (Kelly, 1955), and thus their behaviour and mood is directed by their interpretations and perceptions of events.

2. To a large extent, the cognitive system that generates beliefs about vitiligo is not directly observable. What we do observe is the output of the cognitive-processing system through speech, behaviour and physiological changes.

3. Cultural and social variables are significantly involved in the formulation of beliefs about illness and its consequences (Nelson, 1983).

4. The relationship between vitiligo and psychological state is not linear rather it is a reciprocal system with emergent properties.

These assumptions guide the studies described herein, and an attempt is made to examine the validity of these assumptions with regard to the results of the studies that follow.

1.10 Conclusion

Viewing the body, symptoms, mental processes and the social environment as related components within a single larger integrated system, leads to predictions about skin disease that are surprising and not made by simpler models. The biopsychosocial model challenges us to go further than just acknowledging that multiple systems interact to produce states of health and illness, by providing evidence for the reciprocity between body and mind. In order to do this the contributions of complimentary theories and paradigms that resonate with the biopsychosocial conceptualisation of health and illness need to be acknowledged. The diathesis-stress paradigm, cognitive representations of illness and theories of psychophysiology all serve to help us to understand biopsychosocial principles as they relate to the following studies.

In the discussion that ensues, an attempt is made to underscore the principles posited by the biopsychosocial model by providing research-based evidence of the relationship between body and mind. Although we

have outlined the benefits of the BPS model we have yet to fully understand how it specifically relates to skin disease, and how the various systems interact with regard to cutaneous illness. Further, an attempt is made to examine how vitiligo patients' beliefs are implicated in the way they understand and cope with their illness, and the extent to which cognitive illness representations are implicated in the constructs that patients formulate to explain their vitiligo.

Several predictions are put forward, including the predictions that: the episodic nature of vitiligo can be linked to stress; in the absence of medical information people still form beliefs about disease and that culture is a major determinant of these; and that therapeutic interventions that alter beliefs, such as CBT will alter the psychological sequelae of vitiligo and possibly the physical progression of the condition.

In order to understand the psychological consequences of cutaneous illness and to treat these effectively, there is a need to view the patient holistically, and to address the reciprocity between body and mind. The biopsychosocial model encompasses the theoretical basis of the studies described herein. It acknowledges the complexity of cutaneous illnesses and provides a conceptual grounding upon which the research can be interpreted and examined.

The overriding theme of this thesis is that boundaries between the body and mind become blurred when attempting to understand the mechanisms which underlay skin disease. Although often minimised as 'cosmetic disorders', the psychosocial effects of cutaneous illnesses can be far reaching, and need to be addressed with more than what medical treatments offer on their own. The aim of this thesis is to underscore the reciprocity of the relationship between the skin and the psyche and to explore the implications of this in terms of research and clinical practice.

CHAPTER 2

VITILIGO: A MEDICAL PERSPECTIVE

...and the priest shall look on the plague in the skin of the flesh; and when the hair in the plague is turned white, and the plague in sight be deeper than the skin of his flesh, it is a plague of leprosy; and the priest shall look on him and pronounce him unclean. If the bright spot be white in the skin of his flesh, and in sight be not deeper than the skin, and the hair thereof be not turned white; then the priest shall shut up him that hath the plague seven days...and the priest shall look on him again the seventh day; and behold, if the plague be somewhat dark, and the plague spread not in the skin, the priest shall pronounce him clean; it is but a scab; and he shall wash his clothes and be clean.

Leviticus XIII:3,4,6

2.1 Definition

Vitiligo is a hypomelanotic acquired skin disorder which is characterised by irregular white patches which tend to increase in size over time. Although the appearance of the skin affected by vitiligo can change significantly, the texture of the skin is not affected, nor is the condition considered to be painful or physically uncomfortable (Le Poole et al., 1997).

2.2 History

The earliest reference to vitiligo is thought to be in the *Ebers' Papyrus* 3, 500 years ago which made a distinction between two different types of depigmentations in the skin (Ortonne, Mosher and Fitzpatrick, 1983). The first type had tumors and mutations and the reader was told "thou shalt not do anything about it". About the second it read "thou findest only change of color". The former was most likely a reference to leprosy and the latter to vitiligo. Another early reference is thought to be in the sacred Indian book, Atharve Veda, which dates back to 1400 B.C. where the word "shwetakustha" is used for vitiligo. White patches were also referred to in ancient Greek literature by both Herodotus (484-425 B.C.) and Aristotle (367-312 B.C.) (Goldman, 1966). The geographical diversity of these early reports underscores the widespread incidence of vitiligo.

Although a clear description of leukoderma (white skin) existed among the ancients, the first clear account of leprosy as being distinct from vitiligo was not given until 1842 (Kaposi, 1874). It is thought that much of the leprosy referred to in historical literature is actually vitiligo. This confusion regarding the association between leprosy and vitiligo is still strong in many parts of the world. Indeed up until June 1994, the Oxford English Dictionary described Vitiligo as:

> "a skin disease characterised by the presence of smooth white shining tubercles on the face, neck and other parts of the body, a species of leprosy"

thus perpetuating the literal confusion.

The term vitiligo was thought to have been first used during the 2nd Century AD. It was coined by Celsus who observed that vitiligo patches resembled those of a spotted calf, and used the Latin *vitellus,* meaning calf, to describe the condition (Ortonne, Mosher and Fitzpatrick, 1983).

2.3 Clinical Features

Vitiligo can affect any part of the body and the patches vary in both shape and size. Vitiligo affects all races and both sexes, with an incidence of at least 1% among Caucasoid races (Lerner, 1959b).

Vitiligo develops before the age of 20 in over 50% of cases. The average age of onset is 26 in males and 18 in females (Ortonne, Mosher and Fitzpatrick, 1983). The affected skin is characterised by the appearance of irregular white patches. The skin is otherwise normal and there are no subjective symptoms. Small patches with convex outlines increase irregularly in size and fuse with neighboring lesions to form larger complex patterns. Spreading may occur quickly or may proceed slowly and episodically over many years.

Lesions may appear on new sites and old lesions may spread after prolonged periods of inactivity. Hairs on the affected skin often lose their pigmentation but in some cases retain it (Le Poole et al., 1993b).

Vitiligo lesions can be localized or generalized although the latter is more common. Lesions can appear anywhere on the skin but there tend to be characteristic patterns of involvement. Typically depigmentation occurs around the eyes and mouth, elbows, wrists, lower back, lower extremities and genitals (Seghal, 1984). In some cases the hair in the affected area turns white, this is variable however, with one, few or all hairs losing their pigmentation, and not all macules being uniformly involved.

2.4 Aetiology and Pathology

Vitiligo is a progressive condition involving the destruction of melanocytes within the epidermis. Microscopically it is characterised by a complete absence of melanocytes. The destruction of these cells results in the appearance of depigmentated patches on the skin's surface (Le Poole, 1997). The cause however, is not known, but more than one mechanism may be acting (Ortonne and Bose, 1994; Morelli, 1995). Multiple theories have been put forward as to the cause of vitiligo. The causative factors proposed by each of these theories are not necessarily mutually exclusive and may all contribute to the underlying pathogenesis to varying degrees (Le Poole, et al., 1993a).

(A) Heredity Theory

The first important factor is heredity. Approximately 40% of cases give a positive family history (Ortonne, Mosher and Fitzpatrick, 1983). The patterns of inheritance in vitiligo suggest a polygenic trait, with the involvement of three or more genes (Le Poole and Boissey, 1997). Comprehensive genetic studies are lacking, although it has been suggested that the genetic background of patients may make their melanocytes more vulnerable to cellular damage (Majumder, Das and Li, 1988).

(B) Self Destruction Theory

The self destructive theory posits that melanocytes are destroyed through the failure of normal protective mechanisms to remove toxic chemicals generated by melanogenisis. There is evidence to suggest the existence of intrinsic abnormalities in vitiligo melanocytes. It has been found that melanocytes from vitiligo patients are more difficult to culture in vitro (Puri, Majumdar and Ramaiah, 1989). The melanocytes themselves may contribute to their own destruction through the production of autotoxic substances during melanogenisis. Normally, compartmentalisation in melanosomes protects melanocytes from destruction. However, it is probable that leaky melanosomes could damage the pigment cell.

(C) Auto-immunity Theory

The autoimmune theory stresses the association of vitiligo with other immune disorders such as precocious anemia and thyroid disease. Autoimmune diseases are present in about a third of all vitiligo patients. The strongest associations exist with antithyroid antibodies and antigastric parietal cell antibodies (Lesage, 1997). It has been shown that the infiltration of T-cells and macrophages parallels the loss of pigment and disappearance of melanocytes in vitiligo (Le Poole, van der Wijngaard and Westerhoff, 1993b).

(D) Neurogenic Theory

The neurongenic hypothesis suggests that vitiligo is the result of the accumulation of neurochemical mediators which cause decreased melanin production (Lerner, 1959). As mentioned earlier, both melanocytes and nerve cells use tyrozine to produce an end product, melanin or catecholamines. The similarity of these structures suggests that a translation error of receptor sites controlling the production of melanin may be implicated in vitiligo. Numerous clinical observations have been reported in which vitiligo patients lose pigmentation in areas corresponding to sites of neurological damage (i.e. Ortonne et al., 1983; Lerner, 1959; Panja, 1947). Lerner (1959), described a case where a patient with transverse myelitis and paralysis from the waist down, developed vitiligo on the upper portion of his body and face but not below the point where the spinal cord had been damaged. In a similar case Lerner (1966) described a female patient with diabetes and extensive vitiligo,

who repigmented where she had developed severe diabetic neuropathy. The onset of vitiligo following nerve injuries and anaesthesia has also been reported (i.e. Costea, 1981; Tremiterra, 1927; Pillsbury, 1976; Lerner, 1966). Indeed, many accounts of the onset of vitiligo occurring after a severe emotional trauma such as a bereavement or fright have also been reported in the literature (i.e. Breathnach, 1963; Obermayer, 1985; Ortonne et al., 1983). Reports such as these suggest that the Central Nervous System (CNS) may play a role in the pathogenesis of vitiligo.

2.5 Clinical Classification

The classification of vitiligo is usually based on distribution or localisation of hypopigmented lesions. There are four general types: *vitiligo focalis*- is defined as only a few patches of depigmentation within a limited area of the skin; *vitiligo segmentalis*- is where larger unilateral areas of depigmentation appear which tend to have a quadrant-like distribution pattern; *vitiligo vulgaris*- which is the most common form of vitiligo, is characterised by symmetrical distribution patterns. Lesions primarily involve the body's pressure points, such as elbows, knees and knuckles; *vitiligo universalis*- is where depigmentation involves the greater surface area of the skin.

2.6 Prevalence

The global prevalence of vitiligo is thought to be around 1%, however reports of incidence from different countries have varied from 0.1% to 8.8% of the population. This cross cultural variation in incidence is not thought to be a true reflection of the prevalence of vitiligo, but rather an indication of the differing social significance attributed to vitiligo from culture to culture and also the visibility of the condition on different skin tones (Lerner, 1989).

Vitiligo seems more common among darker skinned populations. In certain parts of India for example, reports of vitiligo have been as high as 8.8% (Behl and Bhathia, 1972). The reports of incidence may also be influenced by the methods used to gather such data. Dermatological out-patients or general in-patients are not necessarily representative of the general population. As Ortonne and his colleagues (1983) indicate, reports between hospitals may vary depending on the degree of interest of particular hospital departments in pigmentory disorders. Further, reliance upon retrospective reports to gather information may give a misleading picture of the prevalence. If, for example, one relies on retrospective reports of hospitalised patients, then an under-estimation of the incidence is likely to occur. This is due to the fact that vitiligo patients are not hospitalised for their condition and that vitiligo is often over looked during in-patient medical diagnoses. Currently, data taken from Europe, India and the USA of the population at large, suggests that incidence is varies from 0.14% to 3.2%, with a world wide incidence of around 1%, and all countries being equally affected.

With regard to sex, males and females are thought to be equally affected, although in some reports women have been reported to have a higher incidence of vitiligo than men (Ortonne, Mosher and Fitzpatrick, 1983). However, this discrepancy may be due to the fact that it is more socially acceptable for women to complain about, or seek treatment for cosmetic disfigurement, than it is for males (Lorber, 1998).

2.7 Age of onset

Although vitiligo is generally considered an acquired condition, there have been some rare cases of congenital vitiligo described (Panja, 1947; El Mofty, 1968). There is very little information available about these cases, but the majority are believed to represent nevus depigmentosus, a congenital hypomelanotic condition, and not vitiligo (Ortonne et al., 1983). The average age of onset of vitiligo is around 20 years, although onset has been confirmed as early as 8 months and as late as 81 years (Lerner, 1959; Ortonne, 1974).

Some reports suggest that the mean age of onset is earlier in females than in males (Ortonne, 1974 Levai, 1958). However, this discrepancy may again be due to the fact that women are more likely to present to their doctor sooner than are men with regard to a skin condition.

2.8 Precipitating Factors

No single factor is known to cause vitiligo. However, between 10%-76% of patients are able to implicate a precipitating cause for their vitiligo. These tend to be either physical injury, (sunburn, trauma etc.) or an emotional upset such as bereavement, ending a relationship or quarrels within the family (Behl and Bathia, 1982). In his detailed studies on vitiligo Ortonne et al., (1983) cites numerous examples of psychogenic factors associated with vitiligo:

> ".....In a young girl with vitiligo, the depigmentation became generalised after an explosion (Queryat, 1922). Another young girl thought she developed vitiligo overnight; the morning she thought she had be nearly hit by gunfire she awakened to notice the presence of macules of vitiligo (Breathnach, 1963). ....after a woman was found to have a malignancy, her father and daughter developed vitiligo (Ortonne, 1974)..." (Ortonne, Mosher and Fitzpatrick, 1983).

The fact that patients may associate the onset of their vitiligo to traumatic life events or injury, may not necessarily suggest a linear causal link between the two. It may be that such events heighten awareness of the body, thus salienating previously unnoticed changes.

2.9 Medical Treatment

Although no cure exists for vitiligo, several treatments are available for controlling the condition. These vary in terms of effectiveness, cost and duration of treatment. Patients reactions to different therapies vary significantly, with some people repigmenting almost completely and others showing no improvement at all, while in other cases a deterioration is seen. Individual differences, such as how long a patient has had vitiligo, the location of the lesions and the colour of the patient's normal pigmentation can contribute to the effectiveness of various therapies. The most common treatments available to patients are outlined below:

(A) Phototherapy

In this treatment, pigemntation is induced through exposure to ultraviolet light in combination with psoralens, this is known as PUVA. Topical PUVA therapy where the skin is 'painted' with psoralens before exposure to light, is recommended for individuals with few well defined lesions of vitiligo. Oral PUVA tends to be used with multiple lesions or when the configuration of lesions makes it difficult to avoid the uninvolved skin when employing the 'paint' method. The probability of repigmentation depends on the location of the lesions. For example, if the lesions are located on the fingertips the chance for cosmetically significant repigmenation is 5% or less. Side effects

of this type of therapy include phototoxic reactions, pruritus, nausea and an increased risk of skin cancer.

(B) Topical corticosteroids

The use of topical steroids to treat vitiligo have been shown to have some success, particularly in patients with an inflammatory component to their vitiligo. These can be used with any age group. The strength of the corticosteroid used will depend on the site and area of the lesions. With stronger corticosteroids there is a higher risk of localised cutaneous atrophy (Le Poole et al., 1993).

(C) Depigmentation therapy

When more than 50% of the body has depigmented, and neither PUVA therapy nor corticosteroids have proven to be useful, then depigmentation therapy can be used to remove residual pigmentation. The end result is uniform depigmented skin which requires photoprotection indefinitely. This process is irreversible and therefore the decision to undergo this treatment should be taken carefully. The process takes several months to a year to complete. Side effects include contact dermatitis, puritus and cunjuctival melanosesn (Le Poole, 1993).

(D) Camouflage

Camouflage make-up to hide the vitiligo lesions is often used instead of medical treatments. These cosmetics work much better on the face than they do on the hands or other parts of the body. One of the drawbacks of using cosmetic camouflage is that it is prone to coming off on surfaces which patient comes in contact with. Also, it often needs re-application throughout the day to prevent it fading.

2.10 Research trends

New research into the aetiology and treatment of vitiligo is being conducted by researchers from a range of academic backgrounds including dermatologists, micro-biologists and practitioners of Chinese Medicine. A large scale study into the use of pseudocatalase (as a substitute for the enzyme catalase which is lacking in people with vitiligo) to stimulate pigmentation is being conducted in Germany, Holland and England by Schellreuter and her colleagues. The results of this study are hoped to be available by the spring of 1998. Research into the transplantation of melanocytes from unaffected areas of skin to depigmented patches is being carried out by David Gawkrodger at the University of Sheffield, results of this study should be available by the end of this year. Raman and her colleagues at King's College London are currently investigating the use of Chinese and

Indian herbs to restore pigmentation (1998). Thody (1998), is currently investigating the growth and function of melanocytes in vitiliginous skin. Al' Abadie et al., (1994a) are continuing their investigation into the effects of neuropeptides on the progression of vitiligo, the first part of this research was published in 1994. During last year a twin study to establish the role of heredity in vitiligo, was conducted by Harper and his colleagues in 1997 at Great Ormond St. Hospital, the results of this study have yet to be published.

2.11 Conclusion

With the first references to vitiligo dating back 1400 BC it is surprising that we have yet to fully understand the mechanisms of this perplexing condition. What is even more surprising is the fact that the stigma that people with this condition face is still widespread with certain cultures still condemning and ostracizing vitiligo sufferers (Lesage, 1997). Vitiligo is not in and of itself a condition which handicaps, it is neither painful nor uncomfortable, yet many sufferers report that the impact that this condition has on their lives is enormous (Porter, Beuf, Lerner and Nordlund,1987; Porter, Beuf, Lerner and Nordlund 1986). It is the disfiguring nature of this condition which handicaps, it is the social and emotional trauma which accompanies an altered body image which affects patients lives and relationships. It is important therefore that in our search for answers regarding the aetiology and treatment of vitiligo that we also look to improve the quality of life of the sufferer. The nature of

this condition suggests that emotional states which arouse the CNS may have a causal link with the condition (Ortonne, Mosher and Fitzpatrick, 1983). If this is the case then there is a possibility that the vitiligo patient may be drawn into a viscous circle where mental state affects the condition and the condition affects mental state. Thus, a more holistic view of the condition, the patient and their surroundings should be taken into consideration when researching and treating vitiligo.

CHAPTER 3

PSYCHOLOGICAL FACTORS IN CUTANEOUS DISEASE: A REVIEW OF RECENT RESEARCH

3.1 Chapter Summary

This chapter explores the relationship between psychology and cutaneous disease and critically reviews recent literature in the field of psychodermatology. Specific areas which are addressed include psychological treatments for cutaneous illness, the effects of psychological variables on the onset and course, of skin disease; an examination of the psychological impact of skin disease on the individual at different stages of development; how the typology of the disfigurement affects coping; and genetic counselling in dermatology. Trends in research in the field are identified and suggestions are made for future research in this field.

3.2 Introduction

Psychological factors have long been associated with the onset, maintenance and exacerbation of many cutaneous disorders (e.g. Bar and Kuypers, 1973; Wolpe, 1980; Engles, 1982). Furthermore, dermatologists and some psychiatrists recognise that a wide range of psychological problems result from dermatological problems. Cutaneous disease is unique in that unlike many other illnesses, it is often visible to others and consequently social factors in coping and adjustment are highly relevant.

The link between dermatological and psychological problems has become more prominent in the published literature (e.g. Al' Abadie, Kent and Gawkrodger, 1994b; Christianno and Uitto, 1993; Elder, Nair, Guo et al., 1994). Research into the more severe manifestations of psychocutaneous disorders such as delusions of paracitosis and dermatitis artefacta, have led to an increasing awareness of the milder psychosocial effects of skin disease. These effects include depression, a decreased sense of body image and self-esteem, sexual and relationship difficulties and a generalized sense of reduced quality of life (Porter et al., 1994; Dungey and Busselmeir, 1982).

The experience of a skin disease is often accompanied by significant changes in a person's physical appearance. The consequences of this are twofold. Firstly, the visibility or prominence of the disease may attract attention in social situations, thus hindering the patient from keeping the illness a private

or personal matter. Further, since skin disease is sometimes associated with contagion or lack of hygiene, the sufferer may find that others react negatively towards them, or treat them differently because of their appearance. Secondly, the physical changes that may develop from skin disease can have a negative effect on body image. Unlike disfigurement resulting from illness or trauma, cutaneous conditions can often be progressive making it necessary for the patient to adapt to a constantly changing body image. The patient may begin to feel socially and physically handicapped and begin to avoid certain situations. In line with these views, recent research has suggested that people who suffer with dermatological conditions have been found to experience higher levels of distress than the general population (Root, Kent, Al' Abadie, 1994; Ramussen, 1990), to avoid social activities, especially those such as swimming where the skin might be exposed (Rubinow et al., 1987; Kent and Al' Abadie, 1996) and to have lower body image and self esteem than the general population (Papadopoulos, Bor and Legg, 1998).

The other major emphasis in this field has been the recognition that psychological health may affect the onset and progress of skin conditions. Although there has been a relatively large amount of published research conducted in this area (e.g. Ginsburg et al., 1993; Koblenzer, 1992; Dungey and Busselmeir, 1982), the links between psychological health and the onset and course of many cutaneous conditions are still not well established. Some researchers have suggested that psychosomatic mechanisms precipitate skin disease in predisposed subjects (MacAlpine, 1954). Others have

hypothesised, that psychologically disturbed patients are likely to present to their dermatologist because of hypochondriasis, delusions related to the appearance of the skin and self mutilation (Sneddon, 1979). Still others have supported the view that the social stigma associated with disfiguring skin conditions might precipitate psychiatric disturbance in otherwise 'normal' subjects (Hughes et al., 1983). There have also been suggestions that systemic diseases such as lupus erythematosus, may produce both skin lesions and psychiatric disturbances. Each of these hypotheses underscores the complex relationship between the skin and the psyche, and the fact that the connection between the two appears to have several functions. The skin not only plays an important role in tactile reception, but also responds perceptibly to emotional stimuli (Van Moaffaert, 1982). Therefore cutaneous disease may also affect tactile communication, sexual interaction and social relationships. Another important link between the dermis and psychosomatics is that skin disease may signal internal pathogenic processes. For example, the diagnosis of meningicoccal meningitis is often made by looking for the petechial or purpuric rash which erupts on the skin. Anxiety and blushing also manifest in the form of changes in the colour or texture of the skin. The skin is metaphorically a door to physical and psychological problems and processes.

The remainder of this chapter examines the complex relationship between psychology and skin disease. Psychosocial morbidity associated with skin disease, psychological approaches to treatment, cutaneous

psychophysiology, genetic counselling in dermatology and the impact of skin disease on social and familial relationships are all discussed and research in these areas is critically examined.

3.3 Cutaneous Psychophysiology

The skin is a complex system made up of glands, blood vessels, nerves and muscle elements, many of which are controlled by the autonomic nervous system, and can be influenced by psychological stimuli. These have the capacity to cause autonomic arousal and the capability of affecting the skin, and the development or treatment of various skin disorders. Evidence of the strong relationship between the CNS and the skin has been demonstrated through stimulation of the CNS which will often produce blushing, pallor and perspiration (Ortonne et al., 1983). These psychosomatic factors often have an impact on the onset and prognosis of many illnesses of the skin.

In their attempt to demonstrate the close relationship between the skin and the CNS, Bethune and Kidd (1961) illustrated how they could initiate CNS (including autonomic nervous system) activity through hypnosis. They suggested that if physiological changes could be produced in a laboratory through psychological stimuli, then common everyday experiences could also produce such responses through similar mechanisms. It is these mechanisms that that the authors suggested were responsible for psychosomatic effects

on organ systems. It has been suggested that people may inherit or acquire a predisposition to a particular cutaneous illness or a basic organ inferiority and that this will determine the way in which a person is affected by the psychosomatic effects of autonomic arousal (Whitlock, 1976). Thus, if one's anxiety response and autonomic response in the skin for example, is heightened, the resulting increase in autonomic activity may have a negative effect on the functioning of the skin. Winchell and Watts (1988) uphold this theory and use psoriasis as an example. They suggest that in the case of psoriasis patients, the skin may represent the weak organ and that increased stress may have an impact on the production of psoriatic lesions by changing autonomic activity. Indeed, if the person becomes stressed or anxious about the disorder than this may result in further over activity in the skin, producing an anxiety response habit.

The psychophysiological mechanisms of other cutaneous illnesses have also been demonstrated. In the cases of urticaria and eczema, suggestions of a psychosocial basis of the illnesses date back to the work of Wilson (1863) and Hillier (1865), who cited mental excitement, nervous debility and anxiety as a cause of these conditions. More recently, in describing the psychophysiological pathways of urticaria, Teshima et al., (1986) suggested that emotional factors probably produce the effects of the illness by causing an increase in vasodialation under the influence of histamine release in the skin. As in the case of other skin conditions which are thought to have a psychological basis, urticaria has been found to respond favourably to

hypnotic suggestion (Whitlock, 1976). In the case of vitiligo, an investigation was undertaken to examine the possibility of impaired catecholamine metabolism in vitiligo patients (Salzer and Schallreuter, 1995). The researchers examined whether patients displayed an increased stress sensitivity to environmental or hormonal changes in relation to a defective catecholamine metabolism. The results of the study indicated that norepinipherine levels in plasma were significantly higher than in controls. Although no specific personality structure was found, divergencies from the normal control were observed in 5 out of the 12 personality dimensions measured. The results of the study suggested a possible link between catecholamine based stress and the progression of vitiligo. However, since the study was of a cross-sectional design, one cannot comment upon whether the increase seen in norepinipherine levels was present before or after the patients had acquired vitiligo. Therefore no firm conclusions can be drawn regarding the role of catecholamine based stress and the onset of vitiligo.

Most studies which attempt to extrapolate the psychophysiology of cutaneous illnesses look to the immune system as contributing mechanism. This is probably due to the common function that the skin and the immune system serve. Both the skin and the immune system serve as protection against foreign organisms. While the immune system fights foreign bodies on the inside, the skin works to protect against invasion from the outside. This occurs on an interdependent basis, and a function of the immune system is to maintain a homeostasis of the body thereby limiting the stress inflicted upon

it. In a study which examined the psychosomatic aspects of skin disease in relation to immunology, Teshima et al., (1982) found that emotional stress had the capacity to influence the immune system to a great extent, and this would often manifest in cutaneous illness. They found that tension in patients could lead to an enhancement of allergic reactions, and that allergic patients improved with autogenic training and relaxation. Further, the research indicated that the function of killer T-cells and the phagocytosis of macrophages were suppressed by induced stress, and that this too had implications for the development of skin disease.

Certain immune responses are visible on the skin, as in the cases of allergic rashes to medication or foods, and certain drug reactions. Interestingly, several psychogenic drugs which have been used to treat dermatology patients have been found to produce allergic reactions in many cases. Eruptions caused by barbiturates, hypnotics and non-barbiturate sedatives are common (Le Poole et al., 1993), especially in cases of overdose. It has been suggested that skin eruption occurs in 4% of all cases of barbiturate coma, increasing to 40% when there is a fatal outcome (Sheridan and Radmacher, 1991). The question regarding the influence of emotional states on allergic mechanisms is still unsettled however. There is evidence to suggest that psychological factors can influence the immune system and that allergic reactions can be altered by hypnosis and the emotional state of the patient (Obermayer, 1985; Sheridan and Radmacher, 1991).

3.4 Psychological Morbidity Associated With Skin Disease

Skin disease is often visible to others, so people suffering from dermatological conditions may be more prone to the social and emotional sequelae. However, psychological factors are sometimes overlooked or ignored by dermatologists, particularly if the skin problems are not regarded as serious or life threatening (Macgregor, 1990), even though 'simple' non-life threatening skin conditions can have severe psychological implications for patients. Jowett and Ryan (1985) interviewed 100 people with acne, psoriasis or eczema who attended a hospital outpatient clinic. They found that patients' lives had been affected in several ways by their skin condition, including difficulties in their self esteem and relationships, reduced opportunities in finding employment, functional and interpersonal problems in the work place, increased levels of anxiety, lack of confidence and depression. Eighty percent of patients indicated that they were embarrassed and self conscious about their appearance and felt that people were likely to stare at them. The view of skin disease as a handicap is not often recognised in the general population and people with skin conditions often face trivialisation of their distress, which can further exacerbate the intensity or seriousness of feelings associated with their illness.

The age of onset of a skin disease may determine the severity of psychological problems and how people cope and adjust (Dungey and Busselmeir, 1982). To examine the effects of skin disease on psychosocial development, Cohen and Nadelson (1971) used infantile eczema as a model. Results from their study indicated that the intimate physical relationship between the infant and a primary care-giver, is sometimes directly affected. This may be as a result of the child's own preoccupation with his/her skin due to discomfort or irritation, or due to the parent's own feelings of repulsion and resentment of the need to apply medicated lotions or soothing creams to a highly distressed child. If the relationship between primary care giver and child is not breached, then implications for emotional and social development will not only have an effect on psychosocial development during childhood but may continue into adolescence (Barden, 1990).

The extent to which a patient will feel stigmatised may also depend on the nature of the skin condition. In their study on the psychosocial effects of vitiligo, Porter et al., (1986) compared vitiligo patients with a matched sample of control subjects with no skin disease, a matched sample of psoriasis patients and a matched sample of patients with other pigmentory disorders involving discoloration. Results indicated that vitiligo patients exhibited better adjustment to their disorder than did psoriasis patients. However, they scored lower than the 'normal' control group on the Coopersmith Self-Esteem Inventory. Vitiligo patients did not differ significantly from those patients with other pigmentory disorders. A possible reason for the difference in

adjustment between psoriasis and vitiligo patients may be that whereas vitiligo patients had to come to terms with the fact that the appearance of their skin changed due to formation of depigmentated patches, the texture and sensitivity of their skin was unaffected. In the case of psoriasis sufferers however, the additional burden of having to cope with dry, flaking skin may compound psychological problems. The fact that both the vitiligo and psoriasis group did not differ on scores on the self esteem scale, but scored lower than the control group, suggests that self esteem may be related more to the cosmetic consequences of a skin condition rather than to the practical needs and sensory changes of the condition. The impact on self esteem for those suffering from skin disease has also been demonstrated in other studies (Cohen and Nadelson, 1971; Jowett and Ryan, 1985).

Specific personality traits in people with cutaneous illness have also been researched. Ginsburg et al., (1993) studied the extent to which anger was implicated in the onset and maintenance of atopic dermatitis, and whether patients felt that they could cope with and manage their anger better than psoriasis patients and matched controls. The results indicated that patients with atopic dermatitis become angry more easily, as indicated by the Siegel Multidimensional Anger Inventory (1986), but were less inclined to display their anger than were matched controls. The patients in this group were also found to be more anxious and less assertive than the controls. However, since the study employed a cross-sectional design it could not be determined whether these personality traits and coping styles were present before the

onset of the illness or whether they were the result of coping with the illness. The efficacy of psychological interventions designed to help subjects manage their anger, was not examined in the study.

Other researchers (e.g. Cole, Roth and Sechs; 1988; Horne, White and Varigos, 1989) have attempted to study the impact of psychological interventions and how these affect the progression of various cutaneous conditions. Cole et al., (1988) examined the impact of group therapy, involving relaxation techniques and behavioural interventions, on patients suffering from eczema. Ten adult subjects received group therapy as a supplement to their regular medical regime. Five symptoms (erythema, lichenification, pustules, excoriations and dryness) were examined biweekly and rated in order to establish a baseline and to measure treatment effects. Patients showed significant improvement in targeted symptoms. However it was not clear whether or not the changes in the patients' condition could be attributed to the group therapy they received. As the authors themselves point out, the small sample size, absence of blind raters to examine patients and the increased time spent with doctors need to be taken into account when interpreting and drawing conclusions from the results.

In a much earlier but similar study, Brown and Bettley (1971), divided 72 eczema patients into two treatment groups. The first received dermatological treatments alone and the second received the same dermatological treatments as well as psychiatric treatment. They found that in cases where

patients displayed overt emotional disturbance, as indicated by psychiatric assessments and psychological questionnaires, brief psychiatric treatment improved the outcome in those with eczema as indicated by the decrease in the proportion of eczema lesions on the patients' bodies. In the absence of such disturbances however, there was evidence to suggest that such treatment could actually worsen the condition. These results should however be interpreted in light of certain methodological shortcomings. Firstly, the methods which the authors employed to distinguish between patients with overt psychological symptoms and those without, may have led to selection bias. Furthermore, as the authors point out, the decision for therapy to run for 4 months was an arbitrary one and this may have lead to poorer results in resistant cases.

As well as examining the effect of counselling on the progression of cutaneous illnesses, researchers have also sought to examine the impact of disfigurement related to skin disease on patients' relationships. Dungey and Buselmeir (1982) considered the psychosocial aspects of psoriasis. Because of it's visibility, the condition evokes a range of responses in those who are confronted by people with the condition. Psoriasis is often considered dirty, ugly or even contagious both by non-affected people and by those suffering from the condition (Jowett and Ryan, 1985). This has implications for both personal and intimate relationships. In an examination of the effect of vitiligo on sexual relationships, 158 vitiligo sufferers between the ages of 16-79 were administered a questionnaire on their beliefs regarding intimate relationships

(Porter et al., 1990). One quarter of those surveyed indicated that they believed that their skin condition had adversely affected their sexual relationships. Between 10 and 15% of those surveyed indicated that their skin condition had limited their ability to find a partner, stating that the number, frequency and location where sexual relationships might occur was also limited. Contrary to what one might expect, the findings of the study also suggested that the majority of patients felt more embarrassed in non-sexual interpersonal relationships rather than in the case of intimate sexual and social relationships. A possible explanation for this may be that since more than half of the sample interviewed were married, with a median age of 38 years, it was likely that they had been involved in long-term relationships. In these cases the issue of their disfigurement was not something new, and potentially, coping mechanisms had already been established. Therefore the possibility of a new sexual encounter was potentially less likely than that of a social non-sexual one. It is reasonable to assume that anxiety would tend to be associated more to the latter situation. The authors of the study suggest that psychological counselling could be beneficial if it addressed self esteem and body image.

3.5 The Typology of Disfigurement Associated with Cutaneous Disease

The way in which a person becomes disfigured will almost certainly have an impact on how they cope with the condition, which in turn may influence how the patient's family may adapt to it. There are three broad categories under which skin disfigurement can be classified: congenital disfigurement; traumatic disfigurement; and disfigurement resulting from disease. Researchers have attempted to examine whether the experience of disfigurement is determined by its cause. In the case of a congenital disfiguring cutaneous condition, early social experiences will generally be affected by a person's appearance. It has been suggested that strangers looking into the pram of a child with a deformity withhold smiles and reinforcing gestures until they have adjusted to the initial shock of the baby's appearance (Field and Vega-Lahr, 1984). Mothers of infants with disfiguring skin diseases often find it difficult to smile or communicate through sounds if they feel unsettled by their child's appearance. As the child grows up, he or she may begin to notice the ambivalent reactions of others towards their appearance. The reactions of other children can be curious, rejecting and often cruel, and the child with an obvious cutaneous illness may grow up with an awareness of being different. The child may become reserved, quiet, withdrawn and non-competitive, or try to compensate for the disfigurement by over achieving at school or at sports (Partridge 1994; Timberlake, 1985). People who acquire a visible skin disease later on in life are faced with

different adaptation tasks than those with congenital skin conditions, particularly if it is on the face and hands. A disfiguring skin disease can adversely affect body image, confidence and, in certain instances, a person's overall quality of life.

The size, contour and location of a lesion or patch of diseased skin may also have an impact on the extent to which the disfigurement will affect the patient's life. If the disfiguring mark is on the torso then the person may avoid sports such as swimming and other activities which may involve exposure of the body. Alternatively if the disfiguring feature is on the face, then the person may have to become accustomed to wearing camouflage make-up, and avoid activities such as water sports which may necessitate removing make-up.

It appears that irrespective of whether disfigurement due to a cutaneous illness is acquired congenitally or later on in life, there is a period of psychological adjustment that the patient must go through in order to come to terms with their appearance. In the case of a traumatic disfigurement or the onset of a skin disease in adulthood, the person goes through a period of mourning for their 'normal' appearance (Partridge, 1994). As they adjust they may experience feelings of shock, denial, anger and sadness, before accepting their new face or body. Mourning for ones lost 'normality' may also be experienced in the case of congenital disfigurement. The disfigured person may be preoccupied with feelings of loss of the person they could

have been (Bradbury, 1996). There may be wide variations in how people cope and adapt to the impact of disfigurement. These variations are not simply a product of the severity of the condition but rather, they are the result of an interaction of variables including social support, social skills, optimism, perceptions of self efficacy and coping style (Lazarus, 1993; Kleber and Brom, 1992; Rumsey, Bull and Gahagen, 1986; MacGregor, 1990). Some people may find the support of friends and family sufficient to help them cope with the challenges of skin disease, while others may require the intervention of professionals to help them cope.

Although a number of charities and societies exist in the UK for persons with cutaneous illnesses (for example, the Vitiligo Society, Eczema Society), limited resources mean that these provide practical support and information rather than psychological counselling. It is important therefore that dermatologists and psychologists work more closely in helping to address the needs of these patients and their families.

3.6 The Impact of Cutaneous Disease on the Family

As in the case of any illness, the impact of skin disease will invariably have an effect not only on the person with the illness but also on his or her family. The diagnosis of a progressive or episodic skin condition within the family can be extremely stressful with both the patient and family being unprepared for the physical and emotional changes that the illness will bring. Skin disease may bring a loss of subjective normality, the family's concept of it's 'self' is altered and new coping methods, role definitions and loss of, or changes in, plans and dreams are all prospects that the patient and his/her family will have to endure (McDaniel, Hepworth and Doherty, 1992, Papadopoulos, 1994).

In their study on the psychosocial effects of psoriasis, Dungey and Busselmeir (1982), found that family members are directly affected by the psoriatic's disease. Parents may blame themselves if the believe the disease to be hereditary and siblings may themselves fear acquiring the disease.

Kerr (1992) used psoriasis as a model to examine the impact of illness on the family emotional system. He suggested that the clinical manifestations of psoriasis are affected by two factors: (1) the degree of adaptiveness and (2) the level of chronic anxiety. Although anxiety may be experienced by individuals, it is also a property of the family system. To some extent, the way in which family members relate to each other is responsible for generating

chronic anxiety. Therefore the higher the anxiety in the family system the greater the strain put upon each individuals' adaptive capacity. The more adaptive family members are, the easier it becomes for one person to become anxious without evoking anxiety from other family members. This way of relating allows family members to become supportively involved rather than withdrawing or becoming anxiously focused on each other. As indicated by the author, if this degree of differentiation is maintained, the family system will be able to successfully adapt to the possibility of future disruptive events or changes.

The relationship between the child and the parent may have implications on the way in which the child makes sense of and copes with his/her deformity or illness. Research suggests that one of the most significant etiologic factors in the development of behavioural problems of children with deformities is the reaction of the parents to the illness or deformity of the child (Barden, 1990; Carey, Donald and Cappelli, 1977). Overprotective parents who shield their child from social ridicule may prevent the development of peer relationships and social skills which are vital for later developmental tasks. Kromberg et al., (1987) examined the response of black South African mothers to the birth of an albino infant. Thirty seven mothers were followed up over a 15 month period. Their interaction with their infant, was compared with a group of matched controls. The results suggested that mothers of albino infants were initially depressed and uncomfortable with close contact with their child and were reluctant to hold and breast feed them. When the mothers were

observed with their infants, they displayed fewer fondling and touching behaviours in comparison to a matched control group. The feelings of unhappiness and depression regarding the appearance of the child persisted, in most cases, until the infants reached 9 months of age. The authors concluded that the birth of an albino infant appeared to cause delay in maternal attachment and resulted in sadness, similar to that experienced by mothers of infants with other congenital disorders.

The realization that the appearance of a child somehow deviates from the norm will almost certainly influence how parents react to and cope with their child's special needs. Common reactions of parents which tend to occur with the birth of a deformed or handicapped child include: (1) parental mourning, i.e. the denial, anger and sadness that the parent feels following the birth of an anomalous child; (2) disappointment shame or guilt with regard to the child's genetic heritage and unmet needs; (3) overprotection or overindulgence stemming from parental anxiety; (4) focusing on the needs of the deformed or sick child and disregarding or downplaying the needs of the other children in the family; (5) parental neglect or rejection of the deformed or sick child; (6) anger or resentment of the financial and time burdens of care taking and medical treatment; (7) parental depression and fatigue (Barden, 1990; Kaplan, 1981; Prugh and Eckhard, 1980; Spinetta, 1981). Barden (1990) indicates that it is generally difficult to ascertain the response of family members, since the complex and often inaccessible feelings of family

members complicate the method through which researchers try to investigate these responses.

It has been suggested that the perception that the family takes of stress or strain, related to the care taking of a sick or deformed family member, is more important than it's objective occurrence (Lazarus and Folkman, 1984). This argument is maintained by research which investigated adaptation to varying types of deformity including cutaneous illnesses, it suggests that children with varying types of handicap or deformity, do not display significantly different average levels of adaptation (Breslau, 1985; Pertschuk and Whitaker, 1985). It appears therefore, that the psychological and emotional well being of children whose appearance deviates from the norm, does not depend on their physical status but rather on differences in family functioning, social support and religious or philosophical attitudes (Hurtig, Koepke and Park, 1989).

3.7 The Role of Psychological Factors in the Onset and Progression of Skin Disease

As well as serving a protective function the skin also has the capacity alert one to internal disease, or even emotional and psychological stressors. Therefore, anomalies on the skin may be indicative of a variety of difficulties including emotional stress, allergic reactions, illness or behavioural patterns such as poor eating habits and lack of sleep.

There is evidence to suggest a higher prevalence of psychiatric disorder in dermatology in-patients and out-patients than in either the general population or a general medical in-patient population (Hughes et al., 1983). Several different approaches have been used to understand the aetiology of psychogenic skin disease. These range from Freudian ideas of hysterical conversion mechanisms (Freud, 1938) to specific neurophysiological disturbances (Sheppard, O'Loughlin and Malone, 1986). In their review of psychogenic skin disease, Sheppard et al., (1986) reviewed 35 cases of dermatological disorders of strictly psychological origin. Of these 35 patients, 8 had dermatitis artefacta, 8 had delusional parasitosis and the remaining 19 presented with skin complaints but displayed no dermatological pathology 'dermatological non-disease'. All but 2 of the 35 patients presented for dermatological rather than psychiatric assessment. The authors suggested that these conditions form an important and common cause of psychiatric

morbidity, and that early recognition is important if treatment is to be successful.

Psychocutaneous phenomena have been classified using a variety of different factors such as specific conflict (Alexander, French and Pollock, 1968), personality (Alexander, 1950) and cutaneous symptoms (Obermayer,1985). Koblenzer (1983) described a classification system for psychocutaneous diseases, comprising of three main categories: (1) conditions that are exclusively psychological in origin; (2) conditions in which strong psychogenic factors are implicated e.g. hyperhidrosis, chronic urticaria; and (3) conditions which are dependent on genetic and environmental factors, but in which the course of disease is substantially affected by stress i.e. psoriasis, atopic dermatitis and recurrent herpes simplex. More recently, Koblenzer (1992) modified her classification system to account for developments in the understanding of the effects of psychosocial stress on immune mechanisms and mediators of inflammation The new classification comprises (1) cutaneous manifestations of psychiatric disease; (2) the effect of psychosocial stress on latent or manifest cutaneous disease; and (3) the somatopsychic effect. There may be difficulties in treating these patients as they tend to resist an explanation linking medical and psychological processes. A possible solution that has met with some success is having a psychiatrist consult conjointly with a dermatologist (Gould and Gragg, 1976; Panconesi, 1985).

Recent research points to a relationship between psychoneuroimmunology and dermatology (Gupta and Voorhees, 1990). Increased central nervous system (CNS) levels of opioid peptides have been associated with psychological stress. Stress also appears to exacerbate certain dermatological conditions which have both psychosomatic and immunological components, i.e. psoriasis, atopic dermatitis (Koblenzer, 1983). Certain psychological traits such as difficulty expressing emotion and denial have also been linked with significantly higher relapse rates in patients with malignant melanomas (Rogentine, 1979).

In a retrospective study which examined the relationship between stress and the exacerbation of skin conditions, Al'Abadie and his colleagues (1994) found that stress was likely to be associated with the onset of a range of skin disorders. Stressful life events identified by patients included family upsets such as bereavement, work and difficulties at school. They suggest that psychological interventions may be helpful for particular patients. It is important to note however that their research was based on retrospective accounts of patients who reported on life events prior to the onset of the disease and thus relied heavily on recall. Further, because of the research design and post a priori hypothesis testing, it is difficult to demonstrate a causal link between stressful life events and dermatological problems.

The effects of psychological stress on the skin has also been the subject of several studies (Greismar, 1978; Papadopoulos, Bor, Legg and Hawk, 1998).

One such study (Greismar, 1978) interviewed patients attending a dermatology clinic and asked about the occurrence of any emotional upsets just prior to the onset of their skin condition. Results indicated a large variation from one condition to another. Skin diseases ranged from those disorders such as hyperhidrosis which always seemed to be emotionally triggered to those such as basal skin cancer that did not seem to have any emotional basis. A main criticism of this research is the fact that his interview method could only detect emotional distress of which the patient was aware and was willing to report.

A classic study which examined how psychological factors are implicated in skin disease is that of Lester et al., (1962). They studied the effects of prescribing tranquilizers and anti depressants to patients with cutaneous diseases. The researchers used a double-blind method. Results indicated that the effectiveness of the drugs in relieving skin symptoms depended on the degree to which the patient had psychological problems. Indeed, tense patients with high anxiety tended to get relief from cutaneous symptoms when they were given tranquilizers. Similarly, depressed patients obtained relief from bodily symptoms when given anti-depressants. Patients with few indications of psychological difficulties showed little improvement in their skin disease after receiving psychotropic medication. While results such as these link psychological influences to skin disease, they are open to interpretation. It might be the case for example, that both physical and psychological symptoms are increased by stress, and that medications which provide a

buffer for stress, relieve both symptoms simultaneously. It is also unclear whether psychological problems are the cause or result of dermatological problems, or whether a linear relationship exists between the two. When depression or anxiety are part of the aetiology or consequences of dermatosis, their reduction by antidepressant or anxiolytic medication can have an indirect benefit on the dermatosis itself. The same indirect action can be presumed for psychotropic medication which reduces irritability dysregulation in self-aggression and tension, all of which lead to dermatitis (Van Moffaert, 1992).

It has been found that a sizeable proportion of patients with dermatological problems are depressed (Obermeyer, 1985). Traumatic life events such as bereavement or reactive depression are considered to be precipitating factors in cutaneous illnesses such as psoriasis and alopecia areata (Fava, Perini, Santonasto and Fornassa, 1980). Although the physiological mechanisms through which these illnesses act are different, they share an important feature in that they are both chronic and visible. Thus, many of the depressive symptoms encountered by persons with these illnesses may be a response to, rather than a cause of the illness (Van Moffaert, 1992).

3.8 Psychological Approaches To Treatment of Cutaneous Conditions

Psychological treatments for skin diseases have ranged from psychoanalysis and the use of hypnosis (Gray and Lawlis, 1982) to cognitive and behavioural therapy (Wolpe, 1980). The literature contains some striking case examples of improvement of skin disease through the use of psychological interventions. One such example is that of a 16 year old boy suffering from congenital ichthysioform erythrodermis (fish-skin disease) (Barber, 1978). The illness had transformed the boy's skin into a thick black crust covered with small pimple like elevations. The boy sought the help of a hypnotherapist who, through suggestion, was able to almost entirely eliminate the disease. Indeed the results were sustained for years after treatment had ended. This is of course the description of a single case study and as there was no attempt to replicate it with other patients, no assumptions can therefore be made regarding the generalizability or indeed the validity of these findings in similar cases.

In their review of psychological therapies for the treatment of psoriasis, Winchell and Watts (1988) describe a case in which two psychiatric patients with psoriasis, receiving the anti-depressant imipramine, are given a suggestion that imipramine will have a beneficial effect on their skin condition. Following this suggestion one of the patients experienced complete remission while the other improved considerably, indeed these results were maintained

as indicated in a four month follow up. In a similar case a man with a 20-year history of psoriasis was treated by Frankel and Misch (1973) using hypnosis and imagery. His condition improved significantly after several months of treatment and this was also maintained for several months. These studies describe specific cases in which no control groups existed and it is therefore important that the findings of this research are viewed in light of this.

Brown and Fromm (1987) have reviewed treatment methods for a number of skin diseases such as acne, puritus, psoriasis, eczema and virus mediated diseases. Psychological interventions have proven useful in each of these types of disorder although there have been few systematically controlled investigations of effectiveness and most of the data in this field comes from small scale studies in which there is no control group. It has been suggested that stress-induced neuroendocrine changes adversely affect the immunity of patients suffering from skin cancer, and as result may be implicated in high relapse rates. Psychological interventions such as suggestion and hypnosis have been shown to have the capacity to enhance immunity (Hall, 1982). Indeed such interventions have also been shown to improve immunologically mediated cutaneous conditions, such as chronic urticaria, dermatitis and viral warts (Barber, 1978; Rudzki, Borkowski and Czubalski, 1970; Surman, Gotlieb, Hackett and Silverberg, 1973). Behavioural and cognitive interventions have also been used in the treatment of dermatology patients. Schoenberg and Carr (1963) helped patients with neurodermatits to learn how to express anger and hostility in more functional ways. Brown and Fromm

(1987) maintain that successful treatment in these patients is directly linked to the patients learning new coping methods which help them deal with their anger. In their paper on psychosomatic dermatology, Gupta and Vorhees (1990), suggest that cutaneous symptoms are a feature of a wide range of psychiatric disorders, including schizophrenia, obsessive compulsive disorder and body dismorphic disorder (Gupta, Gupta and Haberman, 1987). They indicate that psychotropic medication is often used in the management of skin conditions.

Although there is some evidence that psychological counselling can help patients cope with their illness (Horne, White and Varigos, 1989), few investigations have been subjected to systematic investigation, and most have methodological short comings. These include a lack of appropriate control groups, small numbers of subjects and a lack of counselling protocols which aid objective evaluations of outcomes (e.g. Brown and Bettley, 1971; Cole et al., 1988). There is a need for systematic evaluation to determine the efficacy of different approaches to counselling and the development of psychological treatments which will focus on the unique issues faced by those suffering from cutaneous illness. Such investigations should take into account the personal, social and physical aspects of skin disease and seek to integrate these with factors such as cultural beliefs, the family system and the patient care system, so as to develop a holistic approach to counselling patients with cutaneous illness. Theories regarding what may be beneficial in terms of counselling, such as those put forth by Partridge (1994) and

Bradbury (1995) appear very useful, but should be researched with clear and valid methodologies so as to give a clearer indication of their efficacy. The multifaceted interaction between psychology and dermatology is becoming ever more evident and opens up the possibility of a whole sub-speciality of psychodermatology, with research in both fields underscoring the variety and extent of connections between the two. Treatment programmes are highly varied and often appear to be successful, however larger scale systemic studies are still needed in this area until we are able to better understand pathophysiological pathways of skin disorders and improve treatment and care for patients suffering from these.

3.9 Genetics and Skin Disease

As well as being the largest organ on the body, the skin is also the most accessible. Disorders which are so similar that they would be indistinguishable in the lungs, brain or liver can be identified accurately on the skin. The skin can be tested chemically or physically it can be biopsied and grafted and cell cultures can be genetically engineered and restored to the host. All these features make the skin particularly amenable to both gene therapy and molecular genetic research (Moss and Savin, 1995). Research into cutaneous disorders has revealed that several dermatological conditions appear to have a strong genetic component. In the case of vitiligo, up to 40%

of patients are thought to have a family history of the condition (Lerner, 1971). The relative risk for blood relations of affected people is estimated at 12% for siblings and 36% for offspring (Majunder, Nordland and Nath 1993). In a study of the families of 348 Alopecia areata patients, it was found that in 7% of the sample, at least one of the parents had also been affected by the illness, and the lifetime risk of a child of an affected parent developing the illness, was estimated to approximately 6% (Van der Steen, Traupe and Happle, 1992). Genetic factors are thought to be implicated in psoriasis (Elder, Nair, Guo et al., 1994; Watson, 1972; Tomfohrde et al., 1994), eczema (Coleman, 1993; Sandford, 1993) and a range of other skin diseases (Moss and Savin, 1995).

The realisation that a skin disease can be hereditary and can be passed down to children brings with it difficult decisions and challenges for a parent who has suffered with a cutaneous illness. Current treatments for genetic disease aim to minimise the biological consequences of gene mutations. These involve antenatal diagnoses such as chorionic villus sampling, fetoscopy and fetal skin biopsy. Before undertaking prenatal diagnosis with any of these methods however, parents need to be counselled on the possible risks involved in the procedures and on the prospect of facing some very difficult decisions. A decision as to whether the condition is severe enough to justify the risks of the procedure needs to made. Although the doctor may provide parents with information regarding risks, the final decision is up to the couple concerned, who must give their informed consent. The

couple will also need to consider whether or not they will be prepared to act on the results of the tests, personal, cultural or religious beliefs may make them opposed to selective termination.

With the progress of genetic research, new and more refined techniques of antenatal testing are being developed. Future procedures which are being researched include *preimplantation diagnosis* (Christiano and Uitto, 1993) in which a single cell is removed from the eight cell blastocyst stage of in vitro fertilised embryos. The DNA in this cell is then amplified, and checked for mutations in the candidate gene. Only those blastocytes which do not contain the mutation are implanted in the uterus, through in vitro fertilisation methods, thus ensuring that only unaffected children will be conceived. Serious ethical considerations need to be addressed regarding the use of such procedures.

3.10 Trends in Psychocutaneous Research

The methods used over the past three decades to study links between the psyche and the dermis have varied (see table 1). Early research in this field usually took the form of single case studies with few attempts to evaluate the progress of patients after the termination of therapy, or to compare results with those of other patients or matched controls. Outcome measures of these earlier studies have tended to be crude and usually involved the

undocumented observations of a single clinician. Further, outcome measures would often relate either to psychological or dermatological change, but rarely to both. Since the early 1980's, psychocutaneous research has begun to examine outcome from both perspectives, with the majority of research taking the form of controlled trials with large samples and quantitative, cross sectional designs. Currently the majority of research in this field comes from western countries and therefore results relating to variables such as coping and stigma are culturally bound and cannot readily be generalised to other populations.

Table 1. **Selected Studies in the Field of Psychocutanous Research (1961-1997)**

research topic	N	condition(s)	measures	study design	location	reference
effects of hypnotic suggestion on skin disease	2	psoriasis	dermatological assessment	case study	U.S.A	Bethune & Kidd (1961)
psychiatric treatment of skin disease	72	eczema	dermatological assessment	cross sectional control	U K	Brown & Bettley (1971)
psychiatric treatment of skin disease	1	psoriasis	dermatological assessment	case study	U.S.A	Waxman (1974)
effects of hypnotic suggestion on skin disease	1	psoriasis	observations by researcher	case study	--------	Frankel & Misch (1973)
psychological reactions to skin disease	24	leprosy	Hindi adaptation of Middlesex Hospital Index	cross sectional survey	India	Behere (1981)
effects of hypnotic suggestion on skin disease	1	ichthyosiform erythrodermia	observations by researcher	case study	U.S.A	Barber (1978)
psychological impact of skin disease	100	acne, psoriasis, eczema	structured interviews	exploratory analysis	U. K	Jowett & Ryan (1985)
the relationship between stress, family environment and dermatological symptoms in children	44	atopic dermatitis	Life events questionnaire 2 purpose devised, chronic problem checklists; dermatological assessment; family environment scale.	cross sectional descriptive analysis	UK	Gill et al (1987)

Table 1. (cont) **Selected Studies in the Field of Psychocutanous Research (1961-1997)**

research topic	N	condition(s)	measures	type of study	location	reference
effects of group therapy in reducing target symptoms related to skin disease	10	eczema	dermatological assessment	cross sectional control	U.S.A	Cole et al. (1988)
feelings of stigmatization in skin disease	100	psoriasis	stigma questionnaire devised for purposes of study; demographic data	descriptive survey	U.S.A	Ginsburg& Link (1989)
effects of psychotropic medication on psychocutaneous illness	70	unspecified psychocutaneous + anxiety and depression	Hamilton rating scales for anxiety and depression; clinical global impression; cutaneous symptoms (assessed by dermatologist & patients)	cross sectional double blind randomized	Belgium	Heindrickz et al. (1991)
Autonomic Reactivity in dermatology patients	24	psoriasis	heart rate, blood pressure, orthostatic test, Valsava'a maneuver, Stroop test, numerical square test	cross sectional control	Prague	Pankova (1991)
racial variation to physical stigma	158	vitiligo	questionnaire devised for the purpose of the study	cross sectional comparative analysis	U.S.A	Porter & Beuf (1991)
impact of emotional factors on skin disease	94	atopic dermatitis	Spielberg Anxiety Inventory;Siegel Multidimensional Anger Inventory; Gambrill-Richey Assertion Inventory; Beck Depression Inventory; Levenson Multidimensional Locus of Control Questionnaire;	cross sectional control	U.S.A	Ginsburg et al., (1993)

Table 1 (cont) **Selected Studies in the Field of Psychocutanous Research (1961-1997)**

research topic	N	condition(s)	measures	type of study	location	reference
effect of skin disease on psychological distress	22	psoriasis	Psoriasis Disability Index; General Health Questionnaire; dermatological assessment	cross sectional correlational analysis	U.K	Root et al., (1994)
effect of stress and the onset and progression of skin disease	329	psoriasis, urticaria, eczema acne, alopecia, naevi, malignant melanoma, basal cell carcinoma	open ended questionnaire	retrospective qualitative analysis	U K	Al'Abadie et al., (1994)
stress as a trigger for skin disease	1000	vitiligo	structured interview	cross sectional descriptive analysis	India	Behl et al., (1995)
perceived stigma in skin disease	614	vitiligo	Rosenberg Self Esteem Scale; General Health Questionnaire; Dermatology Life Quality Index; adaptated version of Ginsburg and Links (1989) stigma questionnaire; a self report measure of vitiligo coverage	cross sectional descriptive analysis	U K	Kent et al., (1996)
psychiatric illness in patients referred to a dermatology-psychiatry clinic	149	eczema, psoriasis alopecia areata, acne, dermatological non-disease, scratching without dermatological cause; dermatitis artefacta; delusional hypocondriasis	clinical psychiatric evaluation; ICD 10 classification of mental and behavioural disorders; dermatological assessment	cross sectional descriptive analysis	U K	Woodruff et al., (1997)

Some studies, which have examined psychological factors relating to the onset of cutaneous conditions, have relied on the retrospective and subjective accounts of patients. Few studies have been conducted longitudinally to establish the links between psychology and biomedical processes. Indeed, since many dermatological conditions are progressive, longitudinal designs would allow for the examination of the interaction between psychological variables and skin disease across time. Much of the research on stress and the relationship this has with skin disease has focused on objective measures of stressful life events rather than using subjective measures of coping with stress which may be appropriate for use in this context. Further, since the majority of studies have tended to be quantitative in design, much of the depth of information regarding a patient's beliefs about skin disease is invariably lost. Finally, most psychocutaneous research has been conducted on adult samples and very limited information exists in this field on children and adolescents.

3.11 Conclusion

This chapter has attempted to underscore the interaction between psychosocial variables and skin disease. Although we have come a long way in our understanding of the relationship between the two, there is still a need for future research to address those gaps which exist in the field. Particularly, research into the effectiveness of enhancing patients' coping strategies through psychological counselling is needed. Controlled studies should compare differences between the efficacy of different psychological interventions, and examine variables such as length of treatment, and treatment at different stages of the illness. Also needed are carefully controlled studies to compare adjustment patterns of patients with varying types of dermatological disorders and comparisons between these patients and normal control groups. Future research should also look to the development of valid and efficient means for identifying those patients whose psychological mechanisms may predispose them to an increased susceptibility to skin disease. Finally, a closer working relationships between dermatologists and mental health professionals will help to address the psychological needs of patients and their families. It appears that both in the field of psychology and dermatology, there is a movement towards gaining a holistic understanding of the individual rather than maintaining the focus on either mind or body. The recognition that cognition, emotion, motives and behaviour have an impact on skin disease (and perhaps vice versa) opens up new possibilities regarding

assessment and treatment, and the potential for exciting initiatives in the field of psychodermatology in the 1990's and beyond.

CHAPTER 4

Impact of Life Events on the Onset of Vitiligo in Adults: Preliminary Evidence for a Psychological Dimension in Aetiology

4.1 Chapter Summary

The review of literature described in Chapter 3, suggests that various dermatological conditions have been instigated by or have deteriorated due to emotional upsets and stressful life events. Further, the aetiological research on vitiligo described in Chapter 2 gave some anecdotal support for the idea that psychological trauma may precede the onset of the vitiligo. Drawing from this information, the present study retrospectively examined the role of stressful life events in the onset of vitiligo in an adult sample. A matched clinical sample of patients with other forms of disfigurement or skin disease (dystrophic epidermalysis bullosa and naevi) which are not thought to be associated with stress served as a control group. Newly diagnosed vitiligo patients and matched controls were asked to complete the 12 month version of the Schedule of Recent Experience. The questionnaire is concerned with the frequency and number of stressful life events occurring over a specified period. The results suggest that vitiligo patients endured a significantly higher number of stressful life events than controls, indicating that psychological distress may have contributed to the onset of this condition. Implications of the results are discussed and suggestions for future research are made.

4.2 Introduction

Although vitiligo is neither painful nor physically limiting in any way, it can impair a patient's psychosocial functioning, leading to low self esteem, poor body image and poor quality of life (Porter et al., 1990; Kent and Al'Abadie, 1996). Patients have been found to feel depressed, stigmatised and, in extreme cases, rejected by those around them (Behl, 1994a). As previously mentioned, although there has been extensive research conducted into the causes of this condition, (Le Poole et al., 1993; Ortonne et al., 1983; Lerner, 1959) the aetiology of vitiligo still remains elusive.

Several theories have been posited for the possible cause of vitiligo including: (a) the *heredity theory,* where it has been suggested that approximately 40% of cases give a positive family history; (b) *self-destruction* theories, which suggest that melanocytes are destroyed through the failure of normal protective mechanisms to remove toxic chemicals generated by melanogenisis (Puri, Majumdar and Ramaiah, 1989); (c) *immune theories* which stress the association of vitiligo with other immune disorders such as precocious anaemia and thyroid disease (Le Poole and Boissey, 1997) and (d) *neurogenic* causes which suggest that vitiligo is the result of the accumulation of neurochemical mediators which cause decreased melanin production (Lerner, 1959). These factors are not necessarily mutually exclusive and may all contribute to the underlying pathogenesis to varying degrees (Le Poole and Boissey, 1997).

Other studies have suggested that emotional trauma and stressful life events may contribute to the onset of vitiligo (Obermayer, 1985; Ortonne et al., 1983; Breathnach, Bor and Wyllie, 1966), these studies have tended to be limited to single case reports and anecdotal observations. Although clinical observations have suggested that stressful life events often precede the onset or exacerbation of other skin conditions, such as psoriasis, eczema and atopic dermatitis (Al'Abadie, Kent and Gawkrodger, 1994), and although there is believed to be a link between stressful life events and cutaneous disease, much of the research which has been conducted in this area must be viewed as tentative in light of methodological flaws in the design of the studies.

A shortcoming of many of the studies in this field is that they rely on patients' retrospective accounts of their lives several years before the onset of the condition with the attendant problems of recall error and bias. Some studies also look for reasons to account for illness or misfortune after the onset, and emotional stress is a common explanation used (Kent and Dagleish, 1986). Another problem is that the stressful life events reported by dermatology patients are not compared with matched clinical samples whose conditions are not thought to be stress related, thus making it difficult to establish causal links between stress and the onset of cutaneous diseases. Furthermore, some studies which have examined the relationship between stressful life events and skin disease have tended to focus only on negative life events,

when positive life events such as getting married or being promoted might also evoke stress in patients.

There is some evidence that a positive relationship exists between stress and the onset and exacerbation of certain skin conditions (Al'Abadie et al., 1994; Salzer and Schallreuter, 1995). Three groups of dermatology patients, were compared in a study by Al'Abadie and his colleagues (1994). The first group consisted of psoriasis patients, the second group was made up of other dermatological conditions where there is some uncertainty regarding the role of stress (e.g. urticaria,) and the third was made up of patients with conditions thought to be independent of stress (e.g. fungal infections). Patients were asked to complete a questionnaire about whether they believed their condition was preceded by a stressful life event and when these events occurred. Results suggest that psoriasis patients were more likely to report that a stressful life event had preceded the onset of their condition than were patients in either of the other 2 groups. However, the results of this study must be interpreted in light of certain methodological problems. On average the sample had reported that the onset of their condition had occurred between 10.4 and 14 years earlier. Therefore any events that patients had referred to as being stressful were open to memory bias and the possibility of misinterpreting the temporal sequence of events. Also, patients who already held beliefs about the causal relationships between stress and disease would have been more likely to report that a stressful event had preceded the onset of their illness than would patients who did not hold such beliefs. Finally,

since psoriasis has often been associated with stress as a causative or associative factor, those people suffering with psoriasis may have been more likely than the rest of the sample to cite stress as a causative factor.

The link between stress and the onset of skin disease is also demonstrated by the relationship between stress, family environment and atopic dermatitis in children (Gill, Keefe, Sampson, McCaskill, Rodin and Crisson, 1987), where stress and family environment were found to be important predictors of symptom severity in children with atopic dermatitis. However, since parents were responsible for completing questionnaires for younger children involved in the study, it is possible that the parents anxieties and stresses rather than the children's were being reported.

In the case of vitiligo no controlled empirical research has been conducted to establish whether or not psychological stress is implicated in the onset or progression of the condition. If stressful life events are found to precede the onset of this condition then this will have implications for the development of our understanding of the aetiology of vitiligo, and may in turn influence efforts directed at preventing the condition and the treatment that patients receive.

The present study builds on previous findings and attempts to address the methodological shortcomings described above, using vitiligo as a model. Unlike previous studies, the present study focuses on life events occurring no more than 3 years prior to the onset of vitiligo. Furthermore, objective

occurrences of specific life events rather than recollections of feelings about stress are evaluated. This is due to the fact that people are more likely remember events more easily than they will their reactions to events. Finally, a matched clinical sample acts as a control group, allowing reasonable comparisons to be drawn between the experimental and control groups.

4.3 Method

Participants

Participants were over 18 years of age, formally diagnosed by a dermatologist and had acquired vitiligo no more than 3 years prior to taking part in the study. In order to obtain a sample of newly diagnosed vitiligo patients, 2 dermatology hospital units, St. Thomas' Hospital London and The Royal Hallamshire Hospital Sheffield, along with the UK Vitiligo Society[1] were asked to identify newly diagnosed patients and invite them to take part in the research. Participants in the control group were a clinical sample of non-vitiligo patients who suffered from a variety of disfigurements or skin conditions not believed to be associated with stress. These participants were recruited via a letter through the DEBRA (Dystrophic Epidermalysis Research Association) society,

[1] The UK Vitiligo Society is a registered charity which provides information and support to people with the skin condition vitiligo

CLAPA (Cleft Lip and Palate association) and the Disfigurement Guidance Centre.

88 vitiligo patients and 79 non-vitiligo patients returned the questionnaires over an 18 month period. Of these 167 respondents, 10 were discarded as they had not completed the questionnaire correctly or it was incomplete. Of the 88 vitiligo patients 11 had been diagnosed with the condition for longer than the specified maximum 3 year period, and were thus omitted from the study. The remaining 73 vitiligo participants were matched for age and sex with 73 non-vitiligo respondents, making a sample of 146 participants. Of the 73 non-vitiligo patients, 48 had dystrophic epidermalysis bullosa, 15 had cleft lip and palate, 4 had melanocytic naevi and 6 had disfigurement due to trauma or burns.

Design and Instruments

The questionnaire employed a retrospective analysis using a cross section of vitiligo patients and matched clinical controls. The dependent variable was the proportion of stressful life events occurring 1 year prior to the onset of vitiligo, or in the case of controls 1 year prior to taking part in the study, as measured by the Schedule of Recent Experience (SRE).

There has been much debate on the topic of life event scales and what researchers are actually measuring when they employ such scales (Finlay-Jones and Brown, 1981; Thoits, 1983; Brown and Harris, 1989). Central to this discussion is the issue of the term 'stress' as it relates to stressful life events. The term stress is used by some to refer to the external environment and by others to refer to an internal state. Meaning therefore that if stress is something that one experiences it cannot reside in an event, however it can only be construed as stressful in terms of a person's response to a particular situation or event.

Selye (1956) was one of the first theorists to raise the issue of the arbitrariness of listing stressors, and how the effects of these depend not so much on the actual stressor but rather on the way one deals with it. This suggests that events are translated and mediated by certain factors before they are internalised, and 'made sense of'. It has been suggested that a useful way to examine this translation is to address meaning i.e. an internal representation of a person's cognitive and emotional response to these events (Brown and Harris, 1989). In his work on the role of cognitive appraisals and emotion, Leventhall (1980) suggested that emotional appraisals are related to the social appraisals of life events and that perceptions are automatically referred to memories of past emotions and the situations that evoked them. For example, a person who has had bad experiences with authority figures in the distant past, may feel afraid when in the presence of someone they perceive to be an authority figure, though they

may be unaware of the basis of their reaction. Epstein (1983) also emphasises the importance of context and emotion on implicit beliefs and values, suggesting that preconscious material can be brought to the surface through context and/or attention. Although these concepts clearly go beyond the 'shopping list' format of many life events measures including the SRE, difficulty arises in how they are reflected in assessment tools, and how investigators which take into account 'context' make sense of 'meaning'.

Although the contextual approach encompasses more concepts related to the perception of stressful life events, it is this non-specific 'encompassing' that can be problematic. It collapses the event, the social situation in which it occurs and the personal history of the person into a single measure. This results in ambiguity with regard to statistical associations since it is difficult to extrapolate which of the components that go into the ratings are accountable for the associations (Dohrenwend et al., 1987). Further, it is unclear that people responding to life event questionnaires will have the ability to report retrospectively on their response to a particular event, particularly if they have relayed the event to others, as other peoples reactions may affect the response that the persons 'remembers' having. Also, since in this particular case we were concerned with the aetiology of a particular disease, it can be difficult to distinguish between the response to the life event and the response to the disorder itself, especially if the two occurred in close temporal sequence to each other. Although, the validity of 'imposing' general constructs of what exactly a stressful life event is, is arguable, questionnaires

that ask about 'the occurrence of' rather than 'the response to' life events avoid many of the difficulties described above. Further and more importantly, although the use of an objective, stressful life occurrence measure, as opposed to a subjective measure might be construed as a limitation in the present study, it is important to note that vitiligo is an *episodic* condition. Therefore what varies in terms of onset and progress of the condition are not the coping mechanisms employed, which are likely to remain stable, but rather the number of life events which will require these coping mechanisms to be used, which is what the SRE is eliciting.

Instruments

The 1 year version of the Schedule of Recent Experience (SRE) (Amundson, Hart and Homes, 1981) (See Appendix 1) a 42 item questionnaire which solicits identifying data and information about life events was used. These events refer to both ordinary (i.e. taking a vacation) and extraordinary (i.e. gaining a new family member through adoption or reunion) social and personal experiences. Respondents are asked to record the number of times each event occurred over a period of 12 months. The items subscribed to in the SRE by respondents are assigned values from a social readjustment rating scale, and scores are then converted to 'Life Change Units' (LCU) for each respondent. The LCU are calculated by multiplying the item frequency by the scale value given for each particular life event. A cover letter which accompanied the SRE also incorporated a short questionnaire which asked

about demographic variables, age, sex, race, and asked vitiligo patients to state when they first noticed discoloration on their skin and when they were first diagnosed with vitiligo. The section regarding vitiligo was omitted from those questionnaires which were sent to non-vitiligo participants. The SRE has satisfactory validity and reliability and has been used in several studies (Masuda and Holmes, 1987).

Procedure

A power analysis was conducted using DATASIM (Bradley, 1988), in order to determine the appropriate sample size that would enable significant effects to be detected. A power of 0.8 was anticipated. The power analysis revealed that a sample size of 62 or more in each group would be large enough to detect significant effects. The present sample size of 73 in each group, was therefore considered to be satisfactory for the purposes of the study.

Following agreement to participate in the study participants were given or sent the SRE questionnaire which they were asked to complete and post back to either their hospital dermatology unit or to the Department of Psychology at City University, London. The questionnaire was accompanied by a brief letter which explained the purposes of the research. Questionnaires were collected over a period of 18 months, between January 1996 and May 1997. This lengthy process was due to the fact that only newly diagnosed vitiligo patients (no more than 3 years) were required for the purpose of the study. Since the

majority of patients attending the two hospital sites or contacting the vitiligo society had been diagnosed with vitiligo longer than the specified 3 year period they could not be included in the study. Once all the questionnaires had been gathered they were matched for sex and age. Other variables such as ethnicity and education were not taken into consideration since a large proportion of the respondents had not completed the sections on the questionnaire, which asked about these variables.

4.4 Results

The data were analysed using the SPSS statistical package. A Student's t-test revealed that no significant differences existed between the 2 groups with regard to age, (vitiligo group mean age: 37.95 sd 12.57- control group mean age: 40.17 sd 12.94). On average, the vitiligo group had been diagnosed with the condition 1.9 years previously with sd = 1.2. Subjects were matched exactly on the dimension of sex with 38 females and 35 males in each group.

An independent t-test was carried out to examine whether any differences existed on the dimension of Life Change Units (LCUs). The results revealed that the vitiligo group had experienced a significantly higher proportion of life events than the matched controls ($t = 18.28$, $p<0.001$). A frequency count

revealed the most common life events reported by the respondents of both groups. Life events reported by the vitiligo group were compared to those obtained by the control group in order to examine whether any significant differences existed on the individual life events reported. Although both groups seemed to frequently report events such as trouble with employer and changes in financial state, events such as bereavements and personal injury and illness were reported with a much higher frequency in the vitiligo group (see Table 2).

Table 2. Most frequently reported life events of vitiligo group compared to the frequency of same events in the control group

LIFE EVENT	VITILIGO	CONTROL	Chi-square (df=1)*
Major change in financial state	N 26 **35%**	N 22 **30.1%**	χ^2=2.6* p=0.153
Major change in sleeping habits	N 23 **31%**	N 5 **6.8%**	χ^2=7.3* p<0.001
a lot more or a lot less trouble with employer	N 22 **30%**	N 25 **34.2%**	χ^2=3.5* p=0.267
Death of a close family member other than spouse	N 21 28**%**	N 2 **2.7%**	χ^2=8.2* p<0.001
Major personal injury or illness	N 19 **26%**	N 0 **0%**	χ^2=7.5* p<0.001
Major change in eating habits	N 19 **26%**	N 0 **0%**	χ^2=6.7* p<0.001
Change in residence	N 19 **26%**	N 10 **13.6%**	χ^2=2.0* p=0.160
Foreclosure on a mortgage/loan	N 17 **23%**	N 14 **19.1%**	χ^2=2.5* p=0.314
Major change in health or behaviour of a family member	N 14 **19%**	N 2 **2.7%**	χ^2=5.7* p<0.001
Sexual difficulties	N 12 **16%**	N 1 **1.3%**	χ^2=7.2* p=0.012
Pregnancy	N 12 **16%**	N 8 **10.9%**	χ^2=4.4* p=0.236
Death of a close friend	N 10 **13%**	N 1 **1.3%**	χ^2=8.6* p<0.001

4.5 Discussion

The aim of this study was to establish whether vitiligo patients experienced a significantly higher proportion of stressful life events in the year preceding the onset of their condition than matched controls. As predicted, the results suggest that people suffering from vitiligo had experienced a significantly higher proportion of stressful life events prior to the onset of vitiligo than the control sample. Although the most commonly reported life event for the vitiligo group was 'major change in financial state', this was not significantly different to the control group who had a comparably high score on this dimension. This was also the case of life events referring to: 'a lot more/less trouble with employer' and 'foreclosure on a mortgage/loan', suggesting that demands relating to financial and employment issues were uniform across both groups.

Bereavement was comparably the most commonly reported symptom across both groups, with 28% of the vitiligo population reporting the 'death of a close family member other than spouse' and 13% reporting the death of a close friend. These findings are in accordance with those of Harper (1992), who examined precipitating life events in relation to the onset and exacerbation of vitiligo. Eighty four vitiligo patients were questioned, and the most commonly reported precipitating factor was bereavement with 23% of the sample

reporting that they experienced a bereavement prior to the onset of their condition. Unfortunately the study did not employ a control group and therefore no conclusions can be inferred from the results. However, bereavement has been found to be either a precipitating or exacerbating factor in several other conditions such as cardiovascular disease (Williams, 1989; Friedman, 1991), cancer (Kiecolt-Glaser and Glaser, 1987) and various infectious diseases (Jemmott, and Lock, 1984) suggesting that the trauma of experiencing such a loss may predispose people to the onset or exacerbation of various illnesses.

The other commonly reported life events seen in the vitiligo group such as 'major changes in sleeping habits', 'major changes in eating habits' and 'sexual difficulties' may be the product of low mood or depression. These symptoms have been cited in several diagnostic sources, including the DSM-IV (APA,1992), as important indicators of depression. A possible reason for this association may lie in the endocrine changes associated with depressive states. Longitudinal studies have suggested that thyroid hormone levels are raised during episodes of depression and fall during recovery (Kierkegaard and Faber, 1981). Further, endocrine abnormalities have been found to be related to the presence of anxiety (Teshima, Kubo, Imada, Nagata, Ago and Ikemi, 1982). This may be relevant in the case of vitiligo, where one of the most influential theories regarding its pathogenesis is the autoimmune theory. Recent support for this theory comes from the presence of circulating organ specific autoantibodies found in vitiligo cohorts (Grimes, Ghoneum and

Stocton, 1986) and abnormalities in the circulating T-Cell subtypes and natural killer cells in patients with vitiligo (Mozzanica, Foppa, Vignati, Cattaneo, Dioti and Finzi, 1992). Substances such as opioid peptides which have been found to be important in the regulation of the immune system, have been shown in animals and humans to be affected by stress and distress. Since stress also modulates immune responses and natural killer cell activity, this suggests that these substances may be mediators of stress induced immunomodulation, giving further support to the idea that vitiligo may occur following the onset of a stressful life event (Dantzer, and Kelly, 1989; Khansari, Murgo and Faith, 1990).

Factors such as pregnancy and major injury or illness which featured prominently in the vitiligo cohorts results may have been implicated in the onset of vitiligo not solely due to the stress associated with them but also due to the physiological and hormonal changes that are inherent within these events. There is some evidence to suggest that pregnant vitiligo sufferers notice an exacerbation in their condition during pregnancy due to upsets in hormone levels (Ortonne et al., 1983; Lerner, 1959). In the case of 'personal injury/illness' evidence suggests that following a skin laceration, the area surrounding the wound depigments, this is known as the Koebner phenomenon (Lerner, 1959). Furthermore, physical trauma such as sunburn has also been found to precipitate the onset of the condition in some studies (Brown and Harris, 1989).

The final two life events that patients referred to were 'major change in health and behaviour of a family member' and 'change in residence'. The former may be the product of many of the conditions which have been found to be associated with vitiligo within families. It has been suggested that family members of vitiligo patients will have a higher probability of acquiring some form of immune disorder such as thyroid disease, Addison's disease, pernicious anaemia and diabetes, than the normal population (Le Poole, 1997). Thus the 'major change in health and behaviour of a family member' could be due to this comorbidity within families. Change in residence has been cited by several sources as being one of the most stressful life events one can encounter (Brown and Harris, 1989). This is the case not only due to the practical difficulties involved in changing residence, but also due to the possibility of leaving an established social support system, and having to face the anxieties of living in a new neighbourhood and adapting to a new environment. These factors may have therefore caused patients to become stressed and in turn led to the onset of vitiligo via the mechanisms described earlier.

A possible explanation for how the involvement of life stressors can influence vitiligo was recently proposed by Le Poole and his colleagues (1993). They suggested that it may be the case that such stresses lead to an increased production of catecholamines such as adrenaline which can influence depigmentation directly (Shelly and Ohman, 1969). Stress can also cause an increase in corticotropic hormone (ACTH) levels which in turn increases the

secretion of corticosteroids. This in turn can mobilise glucose and free fatty acids which will stimulate insulin secretion. Insulin which directly stimulates L-tryptophan in the brain, can lead to an increased brain serotonin synthesis (Hoes, 1981). Since melatonin is a serotonin metabolite, and hyperactivation of melatonin receptors are thought to play a role in vitiligo (Slominski, Paus and Bomirski, 1989), this hyperatctivation could lead to increased activity of enzymes which are inhibitory to melanogenesis (Le Poole et al., 1993).

It is also possible that the affected person requires a genetic predisposition to the disorder in order for it to develop. As indicated earlier, there is some evidence that heredity plays a role in the aetiology of vitiligo. Approximately 40% of cases give a positive family history (Ortonne et al., 1983), with patterns of inheritance suggesting a polygenic trait, with the involvement of 3 or more genes (Le Poole and Boissey, 1997). The diathesis-stress paradigm provides perhaps the most useful perspective in which to conceptualise vitiligo. This paradigm assumes that individuals inherit a predisposition to particular disorders (*diathesis)*, but that these disorders can remain dormant until some noxious or unpleasant stimulus (*stress)*, either biological or psychological, acts as a trigger to induce them (Meehl, 1962). It is likely therefore, that people are born with a genetic predisposition to acquiring vitiligo (Le Poole and Boissey, 1997) and that the trauma of a stressful life event initiates its onset. Of course the aetiology of vitiligo is yet to be fully understood but the findings described above suggest that further research in

this area would be important in our understanding of the links between mental state and vitiligo.

This study has relevance both for dermatologists and psychologists. From the dermatologist's perspective, the present findings suggest that physicians need to be more aware of the emotional and psychological factors that may have contributed to the onset of their patients' condition. If indeed stressful life events can influence the onset of the condition, it is also likely that they might influence its progression. An awareness of this might guide the treatment that patients receive, so that a more holistic approach to treatment, involving stress management or other forms of counselling to compliment medical therapies, is adopted. From the psychologist's perspective the results of the present study underscore the idea that the psychological stress has implications for physiological functioning, and this might therefore open up new possibilities for collaborative clinical and research activity between psychologists and dermatologists.

Although an attempt was made to overcome methodological shortcomings in the design of the present study, there are certain limitations which need to be taken into account when interpreting the data. Firstly, and perhaps most importantly, information regarding the subjective experience of participants was not taken into account. Although participants were found to have had significantly more stressful life events, it may also be the case that the methods they employed to cope with these events were dysfunctional or

served to maintain or increase the stress responses. As discussed in the introduction, the decision not to ask about coping or employ a method whereby subjective interpretations of life events could be taken into account, meant that the researchers were making assumptions about the effects that life events had on patients. Although the SRE is a standardised measure, it nevertheless makes presumptions about the effects that life events will have. These effects may be unfounded, overestimated or underestimated. It should be noted that the moderating effects of coping strategies could reduce the statistical sensitivity of the design of the present study. Had the results not been statistically significant, the problems of the use of the SRE as a measure of stress would have been a more relevant. Further, certain life events do routinely create strong emotional reactions, particularly bereavement. Moderating effects of coping strategies may therefore explain the lack of difference between the two groups on change in economic status, or problems at work, however these effects may be less significant in the case of bereavement (Brown and Harris, 1989). Ultimately, the most useful type of study to conduct in order to address the present hypothesis would be a longitudinal, prospective analysis. But the relatively low incidence of vitiligo coupled with the fact that there is no certain way of knowing who will develop the condition means that such a study would be extremely costly and time consuming to carry out .

Secondly, with regard to the limitations of the study, since the methodological approach employed was quantitative, it was not possible to allow for any

follow-up interview of participants' reported experiences. This would have been particularly useful since it would have allowed us to comment on mediating factors such as family/social support and coping style used.

Future research should seek to examine whether the results described above can be replicated. It should also attempt to address both the objective and subjective nature of life events in relation to vitiligo, taking into account the coping methods that participants use when dealing with such events. Further, a longitudinal study of people who are believed to be 'at risk' for developing the condition either through inheritance or co-morbidity with other auto-immune disorders, would be useful in examining how life stressors affect the onset of this condition. Finally, the effects of stressful life events and psychological state on the progression of the condition should also be examined, and the impact of psychological therapy as a mediating factor on such events should be investigated.

The results of the present study support the notion that psychological state may have some role to play in the onset of vitiligo. They also give support to the idea that there may be considerable psychological morbidity associated with this dermatological condition. These findings should be taken into account when seeking an explanation for the cause of this complex disorder, and when counselling patients about their condition.

CHAPTER 5

Coping With The Disfiguring Effects Of Vitiligo: A Preliminary Investigation Into The Effects Of Cognitive Behavioural Therapy

5.1 Chapter Summary

The results of the previous study suggested that stressful life events may be implicated in the onset of vitiligo. Drawing from these findings, it would be reasonable to assume that if life events are implicated in the onset of vitiligo, then they also may be relevant in the progression of the condition. Therefore, if one can reduce the impact of life stresses through psychological counselling, this should then impact not only on the psychological/emotional functioning of the patient, but also on the condition itself. The present chapter describes a study which examined the effects of cognitive behavioural therapy on coping with vitiligo and adaptation to the negative effects on body image, quality of life and self-esteem in adult patients. The study also examined whether any psychological gains acquired from psychological therapy would influence the progression of the condition itself. Two matched groups of vitiligo patients were compared, one of which received cognitive behavioural therapy over a period of 8 weeks, while the other received no changes to their treatment status. All patients were assessed on self-esteem, body image and quality of life, prior to, immediately following and 5 months following the end of therapy. The progression of the condition was assessed by photographing

patients prior to the start of counselling and 5 months following counselling. Results suggest that patients can benefit from cognitive behavioural therapy in terms of coping and living with vitiligo. There is also preliminary evidence to suggest that psychological therapy may have a positive effect on the progression of the condition itself. Implications for incorporating psychological counselling into patient care and management are discussed.

5.2 Introduction

Unlike most internal illnesses, skin disease is often immediately visible to others, and therefore people suffering from dermatological conditions may suffer social and emotional consequences. While disfigurement, particularly facial disfigurement, may have an impact on psychosocial functioning (Bull and Rumsey, 1988; Bradbury, 1996), little attention has been paid to the psychosocial problems experienced by people who suffer from skin conditions. Indeed, the psychological impact of skin disease has been particularly under-researched with research in this field tending to focus more on the loss of bodily function and physical handicap.

Most cutaneous conditions are accompanied by pain or discomfort. It is difficult, therefore, when assessing the effect of these conditions on quality of life and self-esteem, to distinguish between which effects are due to these physiological changes and which effects are a result of impaired appearance. Vitiligo is unique in that it presents an opportunity to examine the effects of impaired appearance on patients' lives independent of other physical or sensory changes (Lerner and Nordlund, 1978). It is because of this that many people view vitiligo as a 'cosmetic problem' rather than a medical condition. Both the psychological impact of the condition and the experience of the sufferer may be concomitantly minimised (Porter and Beuf, 1994).

Vitiligo tends to be more salient in darker skinned populations as the white depigmented patches are more apparent against darker skin. This may account for the higher reported incidence of vitiligo among darker skinned populations (Ortonne, Mosher and Fitzpatrick, 1983) and also why many sufferers experience vitiligo as more of a problem during the warmer summer months. There is no cure for vitiligo but several treatments do exist. The most common of these is PUVA treatment which uses psoralens and UVA light to stimulate repigmentation in the skin. The success rate of PUVA varies considerably between individuals and improvements are usually short lived (Ortonne, Mosher and Fitzpatrick, 1983).

Unlike disfigurement resulting from accidents, such as burns, scars or limb amputations, those caused by cutaneous disease can be progressive; patients must not only learn to adapt to the bodily changes they are facing at present, but also be prepared for the possibility that their condition may spread or deteriorate. This is particularly relevant in the case of vitiligo, where the course of the illness is both progressive and episodic. The fact that there is no common trend regarding the progression of the condition means that patients may feel uncertain and unprepared with regard to how they will cope. Another variable which may compound the uncertainty and helplessness faced by a vitiligo sufferer is the fact that there is no known cause for the condition and thus the sufferer will not be able to attribute the onset of the illness to any particular incident or circumstance. Consequently, the vitiligo

patient may live in fear that unspecified behaviours may lead to the appearance of new lesions.

From the patient's perspective the social and emotional impact of a skin condition can be considerable. The feeling of being stigmatised or being different from others is a common reaction and may affect that person's interpersonal and social behaviour. People with cutaneous illnesses which are visible to others tend to be perceived as different from those whose appearance is unremarkable. Indeed, due to the social significance of the skin (Nadelson, 1970), the stigmatisation experienced by people with skin diseases may be the same as, or even more severe, than that experienced by people with other body afflictions (Porter, Beuf, Lerner and Nordlund, 1990).

Self concept and body image are closely related (Bernstein, 1989). Most disfigured people are aware of other's reactions towards them (Cash, 1990), and they must develop and maintain a sense of self-esteem without relying upon physical attractiveness. Jowett and Ryan, (1985) examined the psychological implications of skin disease and underscored the impact that cutaneous conditions can have on a person's psychosocial functioning. One hundred people with acne, psoriasis or eczema, who attended a hospital outpatient clinic, were interviewed about how they felt about their condition. The findings suggested that patients' lives had been affected at several levels by their skin condition, including difficulties in their personal and social life, reduced opportunities in finding employment, functional and interpersonal

problems in the work place, anxiety, lack of confidence and depression. Eighty percent of patients indicated that they felt embarrassed and self conscious about their appearance and felt that people were likely to stare at them. Jowett and Ryan (1985) point out that skin disease is not generally recognised as a handicap and that people with skin conditions often face trivialization of their distress, which can exacerbate the intensity or seriousness of feelings associated with their illness.

As well as affecting psychosocial functioning, mental and emotional state may affect the onset and progress of cutaneous conditions. Research in this area has attempted to classify psychocutaneous phenomena using a variety of different factors such as specific conflict (Alexander, French and Pollock, 1968), personality (Alexander, 1950) cutaneous symptoms (Obermayer,1955), and Koblenzers (1992) classification system which comprises (1) cutaneous manifestations of psychiatric disease; (2) the effect of psychosocial stress on latent or manifest cutaneous disease; and (3) the somatopsychic effect.

As mentioned earlier, there may be a relationship between psychological state and the development of vitiligo. In their study on neuronal markers in vitiligo, Al'Abadie et al., (1994b), indicate that psychological stress increases levels of neuroendocrine hormones, which in turn affect the immune system and the level of neuropeptides in specific regions of the brain. The authors suggest that descending autonomic nerves may trigger the release of

neuropeptides in the skin and that this may explain some of the initial steps in the pathogenesis of vitiligo. In accordance with this, Liu and his colleagues (1996), who studied the occurrence of cutaneous nerve endings and neuropeptides in vitiligo vulgaris, suggest that emotional trauma and stressful life events can cause large adrenal secretions and this can result in the acute onset of vitiligo. Stress also appears to exacerbate certain other dermatological conditions which have both psychosomatic and immunological components i.e. psoriasis, atopic dermatitis (Koblenzer, 1983). Further, psychological traits, such as difficulty expressing emotion and denial, have also been linked with significantly higher relapse rates in patients with malignant melanomas (Rogentine, 1970).

Several studies have examined the extent to which dermatological illnesses affect psychosocial well-being, and how psychosocial well-being affects cutaneous illnesses (e.g. Sheppard et al., 1986; Rogentine, 1970; Van Moffaert, 1992; Whitlock, 1976; Al'Abadie et al., 1994a). The present study builds on previous findings by examining what effect, if any, psychological counselling using cognitive behavioural therapy (CBT) has on the self-esteem, body image and quality of life of vitiligo sufferers, and whether this particular psychological therapy can affect the progression of vitiligo.

The decision to use body image, quality of life and self-esteem as dependant variables was guided by suggestions in recent literature that, the disfiguring nature of vitiligo can often lead to reduced self-esteem and lowered sense of

body satisfaction (Porter et al., 1986; Porter et al., 1987; Al'Abadie et al., 1994a). This reduced self concept has been found to affect overall quality of life in terms of the social and interpersonal activities and behaviours that vitiligo sufferers engage in (Porter, 1990; Kent, 1998). Since it is important to identify not only how these dependant variables pertain to the present research but also to examine the theories which underpin these and how they are related to the present thesis, a brief discussion of each of these variables and the measures used to assess them is outlined below:

Body Image

Body image has a long history of scientific and clinical interest. Most measures designed to assess body image have focused on either perceptual body satisfaction estimates or attitudinal dispositions towards appearance (Thompson, Penner and Altabe, 1990). An important limitation of many of these measures is that they approach body image as a static cross-situational trait, even though specific contexts and events activate processing of information regarding one's appearance and body image. Therefore, the frequency and intensity of negative feelings in relation to body image can vary in response to situations involving body exposure, social comparisons and social scrutiny. This is particularly relevant in the case of vitiligo where the lesions are more apparent in certain types of clothing and during certain seasons of the year. Another issue that many body image measures do not take into account is that positive as well as negative self statements of body

satisfaction are important to consider especially from a clinical perspective where one is interested in examining not only the frequency but also the form that the patients automatic thoughts take (Thompson, 1990).

The Body Image Automatic Thoughts Questionnaire (BIATQ) (Cash, 1990) and the Situational Inventory of Body Image Dysphoria (SIBID) (Cash, 1994), which were used to assess body image in the present study, overcome the difficulties described above. The SIBID takes into account specific contexts where body image disturbance may vary. The BIATQ allows the examination of both negative and positive automatic thoughts and allows comparisons and ratios to be drawn between the two. Further, both are underpinned by a cognitive framework.

Cash (1986) argues that body image is closely related to self concept, the development of which may be influenced by how positively or negatively *we think* others appraise us, "the looking glass self". It may be further influenced by the demands placed on the individual by their social and cultural environment. Subjective evaluations of how well a person's appearance conforms to these demands, can significantly impact self-esteem and body image (Butters and Cash 1987). Therefore the vitiligo may not have to be severe for the individual to negatively evaluate their ability to conform to social standards. These social demands can be physical (i.e. being able to play water sports in the sun without fear of severely burning depigmented skin lesions) or prevailing cultural beliefs and attitudes (i.e. that a tan in the

summer looks attractive and healthy, and that pale skin is unattractive) (Cash and Pruzinsky, 1990).

To a large extent therefore, our satisfaction with our bodies is derived from the way that we believe others to perceive us. In their extensive review on body image research Cash and Pruzinsky (1990) suggest that women tend to have a more pessimistic view of their appearance and weight than is objectively true, they also suggest that people often focus on only the 'unattractive' aspects of their appearance, and body image satisfaction is often based just on those features that the person is unhappy with. They further note that people who were unhappy with their appearance tend to see their bodies as aesthetic objects and minimise their body's utility as a functional instrument.

All of the cognitive interpretations described above can be considered cognitive 'errors' (Beck, 1976): *magnification* of the unattractive feature so that it becomes the focus of ones appearance; *minimisation* of the attractive features and the functional importance of the body and *generalisation* of the undesired feature so that the person begins to see themselves as inherently undesirable. In the same way that one develops cognitive representations of illness and tries to make new information about their illness fit into their existing concepts (see Chapter 1) (Leventhall et al., 1980) so too, do people who have a low body image 'edit' social and interpersonal experiences to reinforce the view of themselves as unattractive (Cash, and Pruzinsky 1990).

For example a person who has an overly exaggerated or negative image about their vitiligo might assume that if someone asks them out on a date it is because they feel sorry for them and not because they find them interesting or attractive.

The stigmatising reactions of others can also have a negative impact on the way in which disfigured individuals conceptualise the effect of their appearance on others (Lansdown et al., 1997). Indeed some researchers have suggested that the effects of stigmatisation may alter the disfigured individuals cognitive processing leading them to perceive even benign responses as hostile (Kleck et al., 1980; Cash and Pruzinsky, 1990).

Both the BIATQ and the SIBID are designed to elicit automatic and negative cognitions about body image. They have been shown to be valid measures of change in treatment outcome studies of cognitive behavioural therapy (Butters and Cash, 1987; Rosen Saltzberg and Srebnik, 1989; Grant and Cash, 1993). Since the concept of beliefs and cognitive representations is one that underpins the research in the present thesis and since the counselling model used in the study employed a cognitive behavioural approach, it was decided that both these standardised measures would be appropriate for the purposes of the present study.

Quality of Life

The emotional impact felt by disfigured people, in attempting to fulfil the cultural demands of attractiveness has been poignantly described by McGregor (1951) as *social death*, a withdrawal from social roles. This 'social death' can affect the activities/behaviours that a person engages in, diminish the amount of social support that the patient receives, and in turn affect the coping resources that one has, to help them deal with their condition (Turner, 1981). It has been suggested that people whose appearance deviates from the norm have a heightened sense of body awareness and pressure to comply with social standards. This pressure has the capacity to affect not only personal and social activities such as relationships and hobbies (Porter et al., 1986) but also quality of life related goals and expectations (Lanigan and Cotterill, 1989). Indeed there is research to suggest that facially disfigured individuals have lower career aspirations (Goldberg, 1975) and more negative expectations about finding a life partner than their non-disfigured counterparts (Porter, 1990).

The literature therefore suggests that quality of life is an important variable to consider in the context of disfigurement and more specifically in this case, skin disease. In the context of the present study the term quality of life is used to describe the impact of disease and disability upon daily functioning.

Until relatively recently, quality of life was defined in terms of length of survival and frequency of symptoms that an ill/handicapped person had to endure, with very little consideration given to the psychosocial consequences of the illness or the effects of treatment (Hollandsworth, 1988). In fact several studies used physician ratings as opposed to patient ratings to assess quality of life (Kaplan, 1985).

Quality of life is of course a subjective experience, which involves various evaluations and value judgements made by the patient. The importance of the subjective nature of life quality was underscored in a study by Jachuck and his colleagues (1982). The authors found that although 100% of the physicians in their study reported that their patient's quality of life had improved following treatment with medication, only half of these patients actually agreed with this. It appears that the results of studies such as these have been heeded, and more recently the measurement of quality of life has placed less emphasis on objective indicators of physical functioning and more emphasis on subjective psychosocial factors. Unfortunately, although theorists agree that the patients subjective experience is 'what counts' when examining quality of life, they have not been able to agree conceptually or methodologically on how to do gauge this.

Questionnaires used to assess quality of life allow patients to relay their subjective experience of their condition, only however, within the confines of the questions generated by the devisor of the questionnaire. Inevitably

important information can be missed by the researcher, such as factors that mediate or compound life quality. Further, establishing reliability and validity for these measures can be difficult. Since quality of life cannot be considered a 'trait' as conceptualised by personality theorists, psychometric methods of reliability assessment may not be directly applicable. Another issue in the evaluation of life quality measures is how they deal with changes in health status over time. This is particularly relevant in general quality of life measures that do not focus on specific illnesses. For example, if someone's quality of life is reduced because they have difficulty walking, this can be the result of something as benign as a sore muscle or as serious as a central nervous system tumour. The distinction between, and psychosocial effect of, an acute non-life threatening condition and a chronic, possibly fatal illness, can not be made by many of these measures because they make no attempt to consider health status over time (Bergner et al., 1981).

Although many life quality measures are designed for use with any disease, some investigators argue that it is important to develop quality of life measures for specific conditions (Meenan, 1982; Kaplan, 1976; Finlay and Khan, 1994). The advantage of these measures is that they are more precise in their description of the impact of a particular disease upon quality of life. However, others argue that it is better to use a general life quality measure simultaneously with disease-specific measures, so that one can assess general function with indicators that are specific for particular diseases. This

argument is more pertinent however in cases where the effects of different conditions are being compared (Liang, 1982).

For the purposes of the present study it was decided that the most appropriate measure to use would be the Dermatology Life Quality Index (Finlay and Khan 1994). This is the only standardised measure of quality of life, which has been developed with a dermatology patient population. It should be noted that, given the fact that the DLQI has been developed for use with various skin diseases, one would predict that people with a mild, physically benign disorder, like vitiligo, would receive lower scores than those with more physically limiting conditions such as psoriasis.

Given the arguments described above, it seemed most appropriate to use a disease specific quality of life measure. Although the points raised earlier are acknowledged as possible shortcomings, it was felt that, the fact that the DLQI has displayed good construct and criterion validity and reliability (Finlay and Khan, 1994), has been developed for specific use for a dermatology population and on practical level, is short and easy to complete would make it a suitable and prudent measure to use with this population.

Self-esteem

The concept of self-esteem comes under the wider construct of self concept. In the field of health psychology, it is a considered a personal resource and it is seen as relevant as it has been found to moderate the effects of disfiguring conditions, incapacitating illness/injury and threatening life events (Bennet et al., 1990). In the field of counselling psychology, it is a seen as a dynamic personality dimension that is affected by a person's interpretation of their world, the extent to which their 'real self' measures up to their 'ideal self' (Rogers, 1969; Cash, 1990) and the way they believe themselves to be perceived by others.

It has been suggested that self-esteem is closely associated with body image (Thompson, Penner and Altabe 1990). Dissatisfaction with a particular aspect of ones self, has been found to cause an overall reduction in self-esteem, The failure to live up to an ideal, in a domain which is considered important to someone's self definition, can be significantly damaging to one's self image (Thompson, 1990).

In the field of disfigurement the relevance of self-esteem lies in the fact that firstly, it is associated with body image which is often disturbed with the onset of a disfiguring condition; and secondly, with the way that self-esteem is implicated in how a patient copes with their condition. It has been found that people who have positive self concepts are more able to cope with both the

reactions of others to their appearance and their own feelings about their altered appearance (Cash and Pruzinsky, 1990). From a cognitive perspective if a person has developed a strong positive self concept then negative or ambiguous social reactions will be less likely to be internalised, and in turn the psychological effects of these will be less negative (Lanigan and Cotteril, 1989).

The Rosenberg Self-esteem Scale (Rosenberg, 1965; 1989) was used in the present study as a measure of self-esteem. This is the most widely used measure for assessing self-esteem in psychology. It was felt that this variable would be important to examine, since literature has consistently suggested that self-esteem is an important factor in mediating and coping with life events including illness and disfigurement (Cash and Pruzinsky, 1990; Thompson and Thompson, 1986). It should be noted however that evaluating concepts like self- esteem quantitatively, brings into question the quality of information derived. This is a short 10 item measure and although this facilitates easy completion, it by no means provides one with the depth or quality of information that would an in-depth or semi-structured interview. The RSE allows one to assess self-esteem at the time of completion of the questionnaire, not how it fluctuates across time nor how external stimuli affect it. It therefore limits the extent to which we can comment upon a persons self concept, or factors which mediate it. However, given the design of the present study it was felt that what was needed was a valid reliable measure that would enable us to assess change due to treatment efficiently at different

assessment points and provide a simple easy measure for participants to complete, the RSE fulfilled these criteria.

CBT was selected for use in this study since it is has been shown to be efficacious for use with body image disturbances in several studies (i.e. Cash and Pruzinsky, 1990; Fisher, 1986; Hutchinson, 1982; Cash and Hicks, 1990; Brown, Cash and Lewis, 1989). Indeed, since positive relationships have been found to exist between body image and self image (Franzoi and Shields, 1984) and between body satisfaction and self-esteem (Cash et al., 1986), it was reasoned that improvements in body image would also have positive effects on self-esteem. Further, the highly structured nature of CBT lends itself most readily to use in a controlled trial. Using less standardised therapeutic approaches would have injected a source of variance into the experimental group alone, thus complicating the statistical analysis. Given the small pool of vitiligo patients available for the study, it was vital to control within group variance as much as possible, in order to maximise the statistical power of the study.

5.3 Method

Participants

Participants were recruited through an advertisement in the UK Vitiligo Society's quarterly newsletter in April 1996. The inclusion criteria for participation required volunteers to:

- be over 18 years of age
- have been formally diagnosed by a dermatologist
- not have previously undergone, or be currently receiving, counselling to help them cope with their condition
- have had the condition for at least one year
- not be taking any form of psychotropic medication.

Twenty one people responded to the advertisement. Of the 21 respondents, 5 were excluded from the study because they had previously received counselling to help them cope with their condition. The remaining 16 participants were matched for age, sex and ethnicity and were then randomly allocated to enter either the treatment group or the control group. The participants allocated to the treatment group received psychological therapy in one of the counselling rooms in the department of psychology at City University, London. Participants allocated to the control group were not offered counselling and received no change to their conventional treatment status. The conventional treatment status of most patients in this sample was either 'no medical treatment', which is a common option for many vitiligo patients since neither steroids or PUVA can be used over extended periods, or PUVA treatment which is the most commonly prescribed medical treatment

for vitiligo (Ortonne, Mosher and Fitzpatrick, 1983). Table 3 summarises the demographic details of the sample, and outlines their treatment status. T-tests were carried out to examine whether any significant differences existed between the two groups with regard to the variables outlined in table 3. No significant differences were found.

Table 3. **Sample Characteristics**

	Control Group	Experimental Group	Total Sample
Males	4	4	8
Females	4	4	8
Mean Age	43.6	37.8	39.9
Asian	3	2	5
Black	0	1	1
White	5	5	10
Years living with Vitiligo (mean)	13.8	16.3	14.2
Cohabiting with partner	5	4	9
Receiving PUVA treatment	2	2	4
Vitiligo Visible when fully clothed	6	8	14

Design

The study employed a mixed 2x3 factorial design. The between-subjects factor was the treatment group: individual counselling versus conventional treatment. The within-subjects factor was the assessment point: pre-treatment, post-treatment (directly following the counselling period) and a follow up at 5 months. Hourly individual therapy sessions with a counselling psychologist were conducted weekly over an eight week period.

A power analysis using DATASIM (Bradley, 1988) was carried out in order to determine the appropriate sample size that would enable any effects due to treatment to be identified. A minimum treatment effect of 0.5 and a power of 0.8 was anticipated. The power analysis revealed that a combined sample size of 14 (7 per group) or more would be large enough to detect such effects. Thus the size of the present sample N=16 (8 per group), was considered satisfactory for the purposes of the study.

Instruments

The outcome measures used were photographs which were obtained prior to and 5 months following counselling and a series of four standardised questionnaires. The photographs were taken in the dermatological photography unit at St. Thomas' Hospital. They were assessed by the researchers and by a dermatologist and a GP who acted as 'blind' raters. All photographs were then assessed by using the AUTOCAD drawing package, which produced objective estimates of any changes present in the photographs prior to and following treatment. The use of this instrument involves tracing around lesions and deriving the area and perimeter of these lesions through computer processing.

The questionnaires used in the study were given to each participant to complete on three occasions: prior to therapy, immediately following therapy and 5 months following the last therapy session. The four questionnaires

used were the following: The Dermatological Life Quality Index (DLQI) (Finlay and Khan, 1992); the Rosenberg Self-esteem Scale (RSES), (Rosenberg, 1965); the Situational Inventory of Body Image Dysphoria, (SIBID) (Cash, 1994), and the Body Image Automatic Thoughts Questionnaire (BIATQ) (Cash, 1990) (see Appendix 2-5) which consists of two moderately independent and internally consistent sub-scales: positive thoughts and negative thoughts. The mean of these scales as well as ratio of the two is calculated in order to obtain an estimate of body image thoughts. Evidence of reliability and validity for each of these measures is satisfactory and reported in several studies (i.e. Ruker and Cash, 1992; Cash, 1993; Rosenberg, 1989; Finlay and Khan, 1994)

Procedure

The counselling protocol used in the study was drawn from the CBT model (Beck, 1976). This model takes the view that it is not situations in and of themselves that are stressful, but rather the perception that one takes of them that makes them so. CBT focuses on examining, and attempting to change, negative thought patterns which may be implicated in a person's low mood or avoidance of certain situations or behaviours. This often involves asking patients to monitor their thoughts, so as to learn to identify automatic negative cognitions. As well as using techniques drawn from CBT, the counselling protocol also incorporated the teaching of practical skills used to help counter negative social attention such as staring, being asked questions about ones

condition and coping with comments from strangers and children (Partidge, 1994; Bradbury, 1996). Table 4 outlines the counselling protocol used for the study.

Table 4.

Counselling Protocol

Assessment Session

- demographic data and family history gathered from the subject
- subject questioned on his/her beliefs regarding the onset, course and meaning of the condition
- subject asked what issues he/she feels will need to be addressed during counselling
- subject asked what expectations she/he has from counselling
- importance of following homework assignments and giving feedback to therapist explained
- and issues of confidentiality discussed
- an explanation of CBT given

Session 2

- issues regarding the onset of the condition discussed /patient's beliefs regarding the illness examined
- patient's experiences following the onset of the illness discussed / patient asked to identify any experiences that he/she found particularly stressful and why
- patient asked what the worse thing about having vitiligo is, both in a real and in an imagined case scenario/possible ways to face such scenarios examined
- relaxation techniques which patient can use when faced with stress or anxiety about the condition discussed
- for homework subject asked to keep a daily record of when the vitiligo has stopped him/her from doing something he/she wanted to do and, to record his/her thoughts about this

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Session 3

- discuss previous week's homework
- discuss what coping mechanisms the patient has found useful when having to deal with condition
- discuss camouflage make-up and when this is used, see if patient feels comfortable being seen without make-up and why
- construct with patient a hierarchy of body parts (moderately satisfied to least satisfied)-use anxiety reduction techniques thinking about each part of the body specifically and then overall body
- do relaxation and imagery of feared situation
- for homework ask patient to continue with daily diary of thoughts related to vitiligo, and to identify a recent occasion where they felt that there condition was stopping them from participating in a activity

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Session 4

- discuss previous week's homework
- ask patient to look at depigmentated part of his her body and speak automatic thoughts that come to mind- help patient identify alternative thoughts- ask patient to reinforce him/herself for identifying these thoughts
- ask patients to discuss any incidents in which they felt they were being stared at or talked about- ask patients to think of alternative reasons why they may have been stared at discuss practical ways of coping with staring
- explore if anything positive had come out of the illness
- for homework ask subject to report experiences in which they felt that their condition was being spoken about or was stopping them from doing things. Ask them to think of alternative reasons for what happened in the same way as was discussed in the session

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Session 5

- discuss previous week's homework
- ask patient to describe two situations which he/she generally avoids when upset about their appearance
- ask subjects to predict what might happen when faced with these situations
- ask subjects to write down rational beliefs to negative predictions
- go through relaxation with patient and do imagery regarding the removal of camouflage make-up
- for homework ask patient to take off camouflage makeup/or clothing used to hide lesions and look in the mirror for 1-2 minutes-ask patient to record feelings following this activity-also ask patients to practice relaxation techniques which were discussed during session

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Session 6

- discuss previous week's homework
- introduce subjects to the concept of engaging in behaviours that give a sense of mastery or pleasure, to help them view their body for its capabilities, and not only for its relevance as an aesthetic object
- ask patients what their thoughts are about this
- for homework ask subjects to rate the frequency of involvement in physical activities and rate these activities in terms of mastery and pleasure
- for homework ask patient to enter one of these situations while thinking of rational beliefs and rehearsing positive thoughts

Session 7

- discuss previous week's homework
- discuss degree of handicap: social /occupational/leisure which they feel is associated with the condition
- discuss changes in lifestyle that have been made since the onset of illness
- ask patient to speak about themselves and lives without mentioning their condition
- for homework ask patient to write out counter-arguments for beliefs regarding illness

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Session 8

- review homework from previous session
- review basic components of programme and techniques for post treatment maintenance gains
- address any stresses patient has in terms of ending treatment
- review any improvement subject has made and discuss stress inoculation and relapse prevention procedures

Prior to the start of the study, a detailed letter was sent to volunteers outlining what the study would entail, and indicating that participants would be required to complete a series of questionnaires and, depending on their treatment status, have their photographs taken on 2 separate occasions. Participants were sent the questionnaires through the post a week prior to the start of the study. They were given written instructions on how to complete the questionnaires and were asked to return them as soon as possible by post. Questionnaires were sent to all participants again at the end of the 8 week course of therapy and for the final time at 5 months following the end of therapy. Each questionnaire included clear information on how it should be completed.

In the letter which patients received prior to the start of the study, they were asked whether they would be willing to have their photographs taken for the purposes of the study. It was explained to all participants that the photographs would be taken at the dermatological photography unit at St. Thomas' Hospital, by a medical photographer, and that all photographs would be handled with strict confidentiality. Patients were asked to have full body shots taken. However, since many indicated that they only felt comfortable photographing areas of their body which were affected with vitiligo, they were given the choice to do so. It was agreed by participants that if their vitiligo migrated to other parts of their body during the course of the study that the new lesions would be photographed in the final photographic assessment

phase. Finally, it was indicated to patients that if they were receiving any form of treatment for their vitiligo (i.e. PUVA, steroids, pseudocatalayse), that they would not be eligible to have their photograph taken. This was done to ensure that any changes seen in the development of the condition could not be attributed to medical treatments the patient's were receiving for vitiligo. Of the 16 participants only 12 were eligible to have the progression of their vitiligo assessed through photographs however, since the other 4 were receiving PUVA treatment. Of these 12 only 11 agreed to be photographed, leaving a sample of 6 participants in the experimental and 5 in the control group for this part of the study.

5.4 Results

A multivariate mixed analysis of variance (MANOVA) was carried out using SPSS, with time (within participants variable) and treatment (between participants variable) as the independent variables and self-esteem, quality of life, body image automatic thoughts and situational body image as the dependent variables. Significant main effects of treatment (Pillais Bartlett Trace= 0.972, F= (4, 4) 96.8, $p<0.001$) and time (Pillais Bartlett Trace= 1.53, F= (8, 8) 20.9, $p<0.001$) were observed. As predicted, there was also a significant multivariate interaction (Pillais Bartlett Trace= 1.60, F= (8, 8) 26.7, $p<0.001$).

The significant multivariate effects were followed up by univariate ANOVAs on each dependent variable separately, using the Bonferroni correction for multiple tests. The latter requires individual significance levels of 0.0125. The univariate results are summarised in table 5.

Table 5. **Univariate ANOVA Results**

SIBID	F	df	p
TREATMENT	131.97	1, 14	<0.001
TIME	117. 91	1, 14	<0.001
TIME x TREATMENT	206.43	1, 14	<0.001
RSES	F	df	p
TREATMENT	120.28	1, 14	<0.001
TIME	74.65	1, 14	<0.001
TIME x TREATMENT	156.90	1, 14	<0.001
DLQI	F	df	p
TREATMENT	134.80	1, 14	<0.001
TIME	93.32	1, 14	<0.001
TIME x TREATMENT	168.12	1, 14	<0.001
BIATQ	F	df	p
TREATMENT	133.67	1, 14	<0.001
TIME	93.2	1, 14	<0.001
TIME x TREATMENT	168.12	1, 14	<0.001

As can be seen from table 5, all univariate main effects and interaction effects were significant. The interaction effects were followed up with two sets of simple effects, those of group at each level of time and those of time within each group. The effects of group at the pre-treatment assessment point were

non-significant for all dependent variables (DLQI, RSES, SIBID, BIATQ). The effects of group at the post treatment and at the 5 month follow-up assessment points, were significant for all dependent variables. No significant changes were observed in the control group between assessment points. However, as indicated by the results in table 6, there were significant improvements observed in the treatment group on all four measures following counselling and these improvements were sustained at the 5 month follow-up assessment. Participants' scores from the treatment group had moved into the normal range on all four measures. Post hoc tests using the Scheffe test were carried out on time in order to determine the point at which change occurred. These showed that significant changes occurred between the pre-treatment and post-treatment assessment points for all dependent variables. There were no changes between the post-treatment and the 5 month follow-up points with the exception of the RSES which showed a further improvement in the treatment group (see figure 4 tables 7-8).

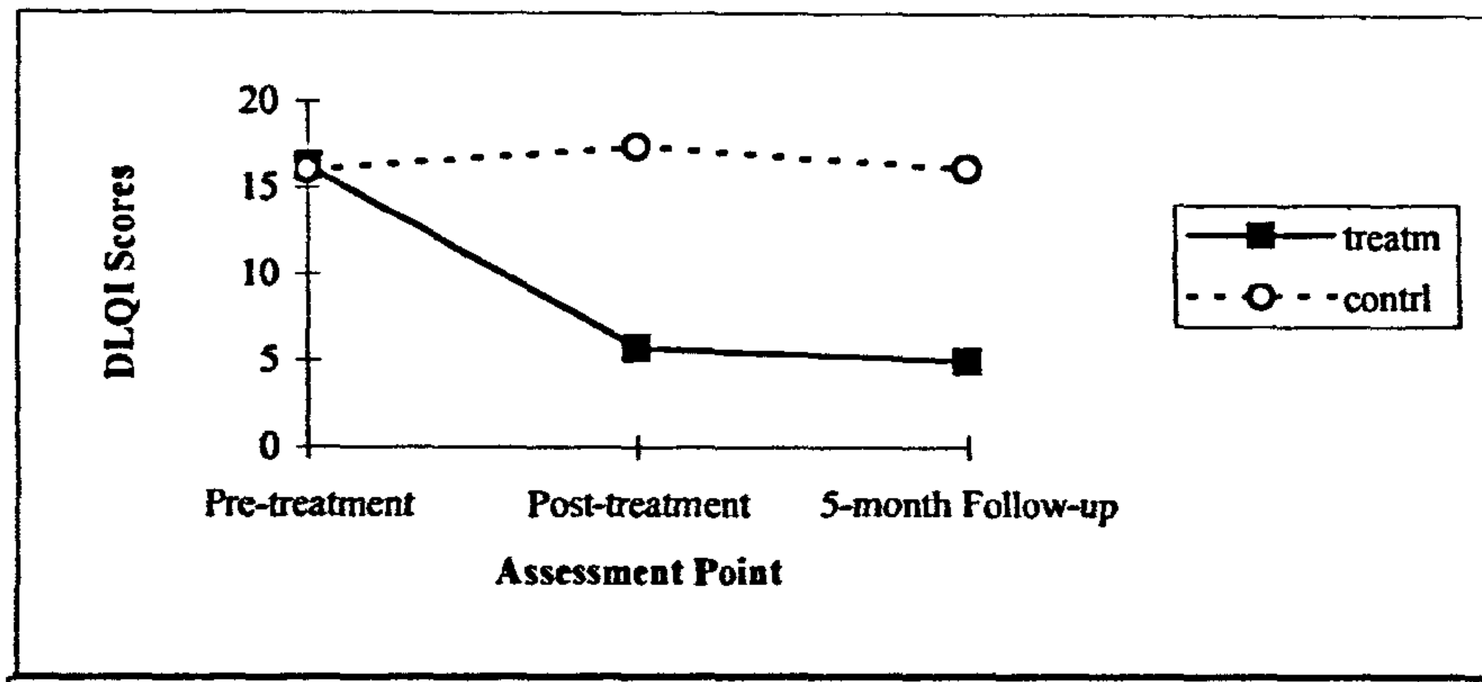
Table 6 **Results of Simple Effects for Treatment Group**

Test	F	df	p
SIBID	135.77	9, 14	<0.001
RSES	119.20	9, 14	<0.001
DLQI	141.00	9, 14	<0.001
BIATQ	69.95	9, 14	<0.001

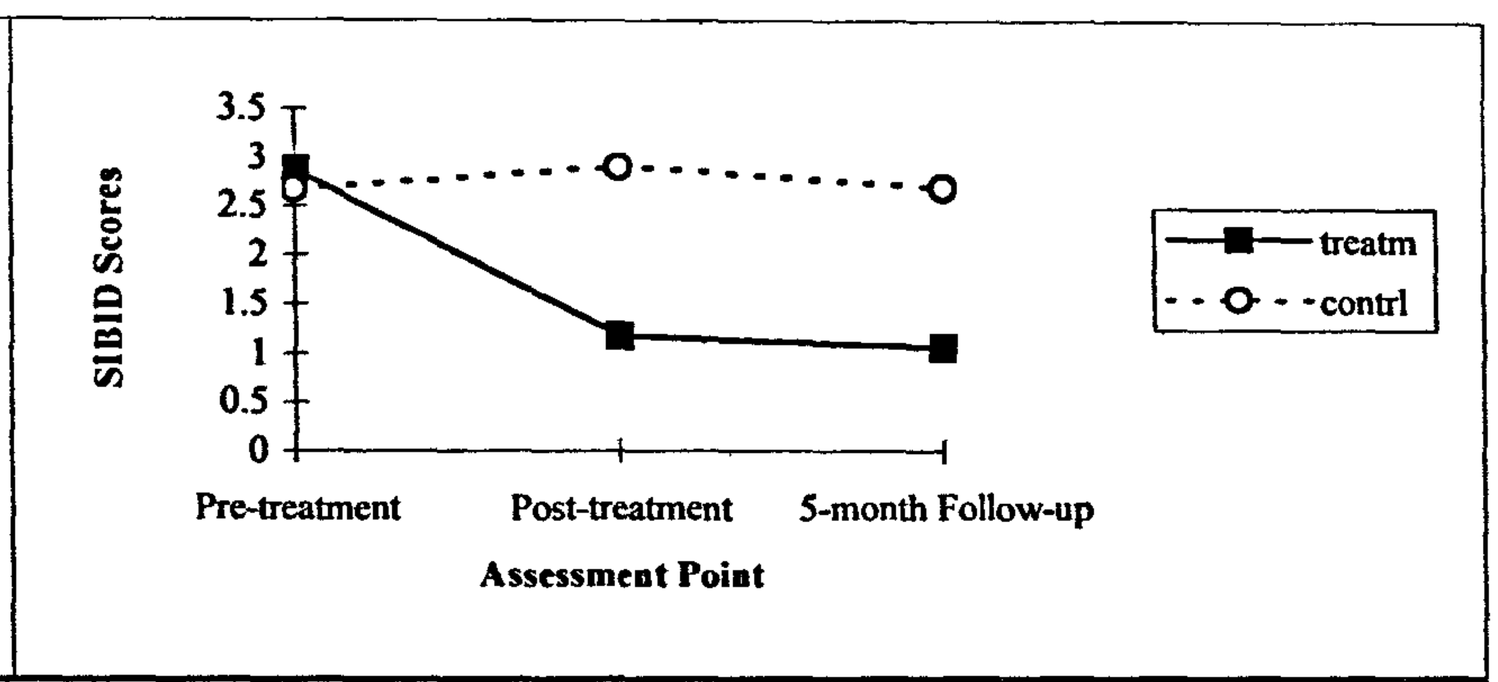
Figure 4

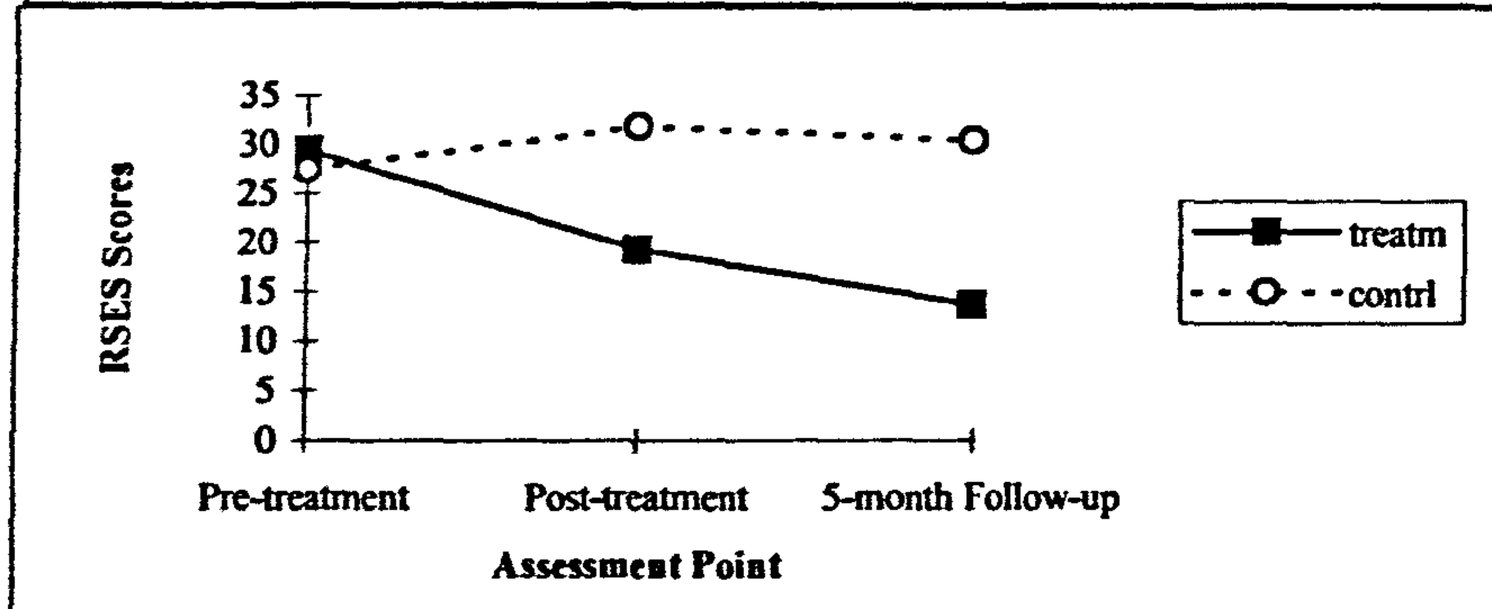
Means Obtained Prior to, After and 5 Months Following Counselling

A

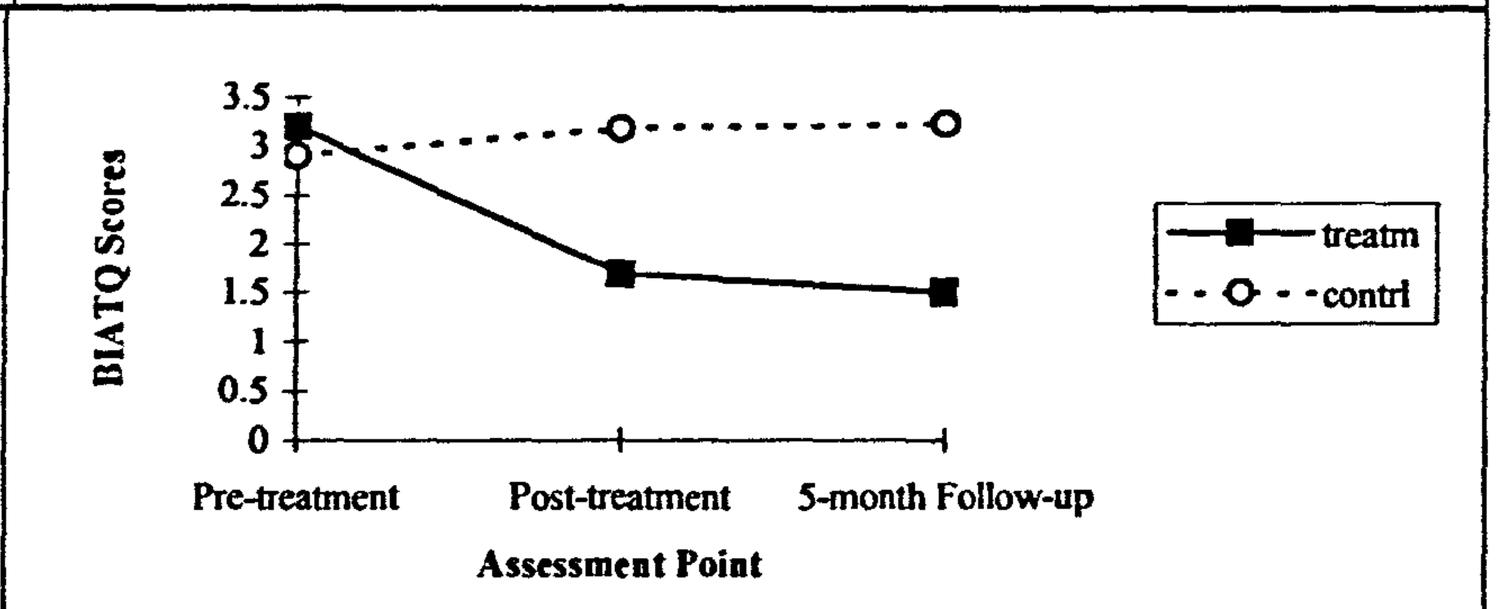


B





C



D

A: Scores obtained on the DLQI by the treatment and control groups at each assessment point in the study
B: Scores obtained on the SIBID by the treatment and control groups at each assessment point in the study
C: Scores obtained on the RSES by the treatment and control groups at each assessment point in the study
D: Scores obtained on the BIATQ by the treatment and control groups at each assessment point in the study

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Table 7

A Comparison Between Means Obtained From the Study and Published Norms

Questionnaires	Norms		Pre-treatment results-control group		Pre-treatment results-treatment group		Post-treatment results-control group		Post-treatment results-treatment group	
	mean	s.d	mean	s.d	mean	s.d	mean	s.d	mean	s.d
DLQI[1]	24.2	20.09	16.00	2.88	16.25	1.39	17.38	2.45	5.75	1.28
SIBID	1.38	0.68	2.67	0.20	2.87	0.43	2.91	0.19	1.18	0.38
RSES	34.73	4.86	27.38	1.77	29.38	2.07	31.88	1.25	19.25	2.49
BIATQ positive thts	2.64	0.82	3.05	0.15	3.10	0.18	3.03	0.18	3.18	0.24
negative thts	1.80	0.63	2.92	0.31	3.27	0.46	3.26	0.28	1.69	0.23
ratio	0.41	0.11	0.49	0.02	0.53	0.04	0.50	0.03	0.36	0.04

Table 8

Results From the 5 Month Follow-Up Study: A Comparison Between The Treatment and Control Group

5 MONTH FOLLOW-UP				
	SIBID	DLQI	BIATQ ratio	RSES
Control Group	2.69	16.13	0.62	30.38
Treatment Group	1.06	5.00	0.31	15.75

[1] Norms given for this measure are derived from a population of dermatology patients not healthy controls. The mean & s.d. given for a healthy controls with no skin conditions is 1.6 with sd of 3.5.

Table 9

BIATQ: A Comparison of Positive and Negative Thoughts Between The Control and Experimental Groups

Groups	Pre-treatment Means		Post-treatment Means	
	positive thoughts	negative thoughts	positive thoughts	Negative thoughts
Control	3.05	2.92	3.03	3.18
Treatment	3.10	3.27	3.26	1.69

changes in lesion size

Following the completion of the second and final set of photographs, both sets were shown to two 'blind' independent raters, a dermatologist and a general practitioner, with an interest in dermatology. Each independent rater was asked to observe the before and after photos of each of the 11 participants and comment on them independently. They were not told which photographs were taken before or after treatment, nor were they told that any changes between the photographs existed. They were asked to examine each pair of photos and comment on any differences between the 2 that they observed. Both independent raters indicated that they observed changes in the same 5 cases. In three cases, which were part of the treatment group, the raters indicated that they observed an improvement. That is, they noticed a reduction in the size of vitiligo lesions. In the other 2 cases they observed a

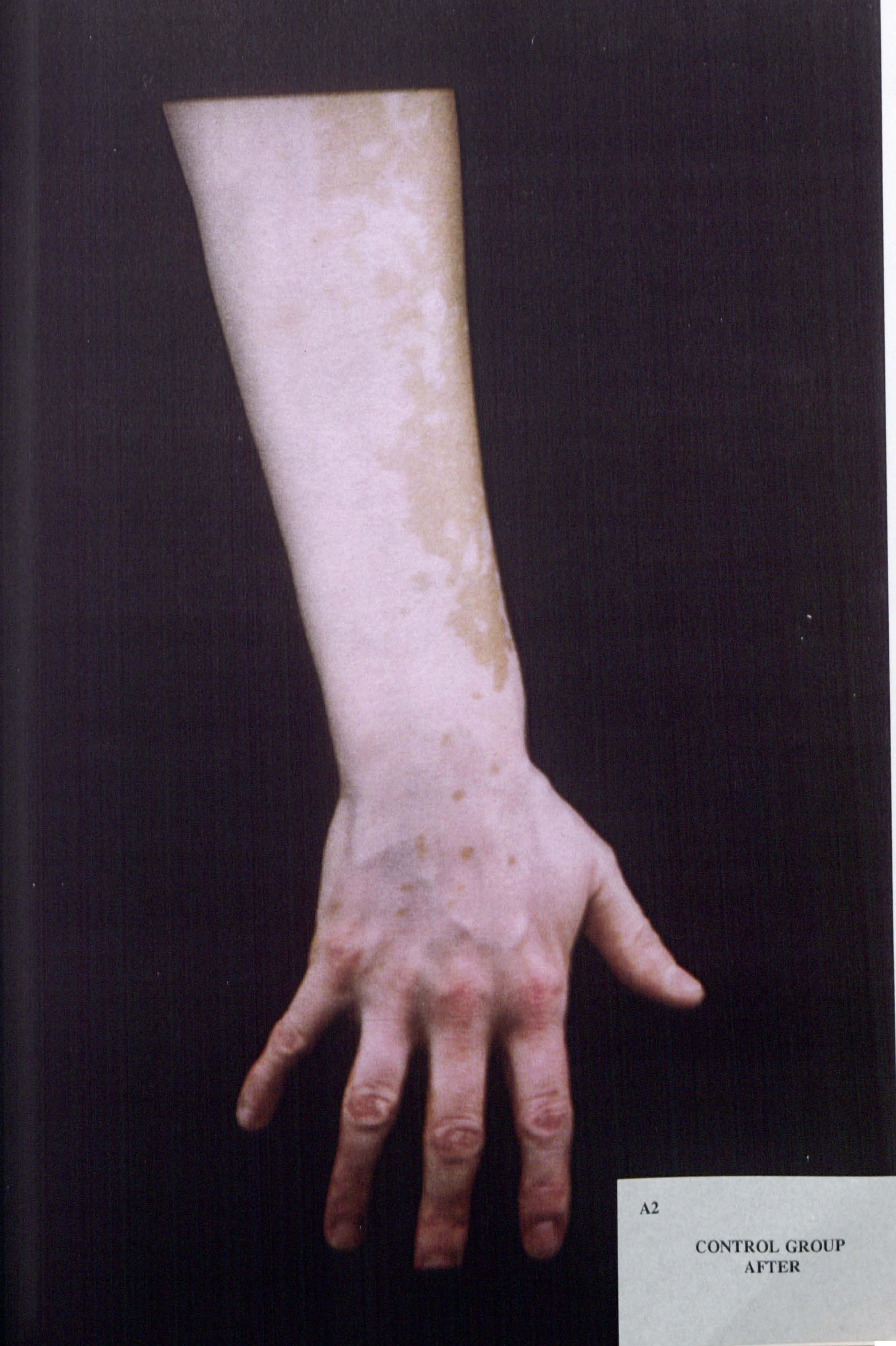
deterioration in the condition of the patients, in that there appeared to be an increase in the size of vitiligo lesions. The latter 2 cases were part of the study's control group. All cases including those cases which had been identified as having changed, were assessed using the AUTOCAD drawing package, so as to obtain an objective estimate of the extent of change. It should be noted that although this is a quantitative, unbiased measure for change, that some minor measurement error is inevitable due to errors in tracing the lesions between photographs. Photographs *A1-D2* give the before and after results of 4 of the participants.



A1

A1

CONTROL GROUP
BEFORE



A2

CONTROL GROUP
AFTER

B1

CONTROL GROUP
BEFORE

B2

CONTROL GROUP
AFTER

C1

TREATMENT GROUP
BEFORE





C2

TREATMENT GROUP
AFTER



D1

TREATMENT GROUP
BEFORE

D2

TREATMENT GROUP
AFTER

D2

TREATMENT GROUP
AFTER

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As mentioned, not all of the patients had agreed to have full face and body shots taken. Thus, in order to obtain unbiased results it was decided that lesions would be chosen randomly for each of the patients to assess change, rather than focusing just on those areas which had been identified as having improved. In order to do this, different areas of the body, as displayed on the photographs, were allocated a number. A number was then chosen at random for each participant which corresponded to the area of the body which would be assessed. The results obtained from AUTOCAD confirm what had been observed by the raters. The vitiligo lesions of 3 participants in the experimental group had reduced in size as defined by the area of the lesion by 26.20 %, 25.77% and 34.93 % respectively. The lesions of 2 participants from the control group increased in size by 50.63% and 33.08% respectively. The remaining 6 participants showed a change of 0.29%, 0.60% and 1.01% for the treatment group and 0.54%, 0.94% and 0.32% for the control group. These changes are most likely due to measurement error which occurred during the tracing of the photographs when the analysis was being carried out.

As the changes in lesion size were distributed bimodally in both groups the numerical data were converted to categories for subsequent analysis. The categories were: 'no change', 'improvement' and 'deterioration'. A likelihood ratio test was used to compare the two groups because it is sensitive to low expected frequencies. The results of the likelihood ratio test suggest that the change in the size of the lesions was statistically significant at the level of

$p<0.05$. Further, it was found that those cases that had been identified as having changed by the researchers and the blind raters, were the same cases where a change in lesion size was observed using AUTOCAD, suggesting a high correlation between the clinical judgements and results obtained using a quantitative measure.

5.5 Discussion

Results from the present study suggest that counselling can help to improve the body image, self-esteem and quality of life in patients with vitiligo. Participants reported feeling more in control of their condition and more able to cope with its challenges. There is also preliminary evidence to suggest that gains made through counselling influence the progression of the condition itself. The psychosocial clinical gains evidenced from the study reinforce the improvements seen in the questionnaires. Following therapy, participants in the control group were able to undertake previously avoided behaviours such as wearing clothing which revealed their vitiligo lesions, going out in public without camouflage make-up, and being able to talk more freely about their condition. During the course of therapy, there was an effort made to encourage clients to discuss what they might do on occasions when they were feeling 'low' about themselves or their condition and where they could seek support from once therapy had ended. The researchers felt that this

was particularly important in terms of helping participants to maintain gains following the completion of therapy. This may indeed account for the sustained levels of improvement observed during the five month follow-up. Moreover, it may account for the increase on the self-esteem measure following the end of therapy.

An interesting feature of the results lies in the outcome of the Body Image Automatic Thoughts Questionnaire. As mentioned, this measure allows the 2 sub-scales (positive and negative thoughts) to be split and measured separately. It appears that the CBT used in the study had a greater impact on the reduction of negative thoughts, where a significant improvement was seen during counselling, rather than an increase in positive thoughts, where no significant improvement was observed (see Table 9). This implies that vitiligo patients do not have less positive thoughts than the general population but rather an increase in 'irrational' negative thoughts. This is accordance with the findings of Hart (1982), who found similar results with depressed and anxious patients.

Although one would have expected significant reductions in self-esteem, body image and quality of life to occur across the sample during the height of the summer months, this was not observed. The summer is often experienced as a particularly stressful time for vitiligo sufferers since exposure to the sun not only makes vitiligo lesions more obvious but can also prove to be painful due to the lack of pigmentation in the skin which makes vitiligo sufferers more

prone to burns. The fact that the experimental group were able to make the gains they did during this period, may be seen as further evidence of the usefulness of CBT as a tool for patients with vitiligo.

In view of the small sample size it was not meaningfully possible to break down the sample further into sub-groups and test for differences with regard to age, sex and race. Future research should seek to investigate this with the use of a larger sample. The fact that the improvements in the experimental group were maintained and in the case of self-esteem improved further following the end of treatment, suggests that the efficacy of the therapy lay not only in the comfort and safety of the counselling relationship, but also in the practical cognitive tools and sense of mastery that the patients felt they had acquired through the counselling process. The directive nature of CBT provided an environment where patients were encouraged to practice, rehearse and master tools for coping with their condition, and it appears that these served to help participants maintain the initial gains acquired through counselling. However, since the only counselling model used in the study was CBT no conclusions can be drawn as to the efficacy of different types of counselling such as psychodynamic, person centred, group or family therapy.

The changes observed in the appearance of vitiligo lesions of certain patients suggests that gains acquired through counselling may influence the advancement of the condition. Vitiligo is a progressive condition but it does have episodes of dormancy and in limited cases, improvement (Ortonne et

al., 1983). The fact that there was no deterioration in the experimental group and observable improvement in 3 of the 6 cases, while 2 of the 5 participants in the control group deteriorated considerably, suggests that there may have been more than chance factors acting on the development of the condition. Indeed, the likelihood ratio test revealed that the changes seen in the size of lesions were statistically significant. It should be noted however, that assessing change objectively in dermatological conditions is not an easy task. Even when professional photographs are used, one has to rely on a two-dimensional surface to examine a three-dimensional object, which complicates perception of the image. Further, variables such as lighting and the distance from which photographs were taken may also affect perception of the image. The present study tried to overcome these difficulties, and reduce the possibility that they would confound the data by including 2 independent raters who both had experience in assessing change from photos, by using a computer drawing package as an objective measure and by randomly selecting lesions to examine.

Although only a small number of patients were involved in this part of the study, the robust nature of the results suggests that future research with a larger sample, would be of value so as to allow for possible generalisations to be made regarding the connection between mental state and vitiligo. As mentioned earlier, there have been suggestions in the past that psychological and emotional well being do in fact influence the progression of various skin conditions (Gupta and Voorhees, 1990; Al'Abadie et al., 1994a; Koblenzer,

1983; Fava, et al., 1980). Future research should seek to examine the utility of different therapeutic models such as person centred therapy or family therapy, both in the context of counselling people with skin disease and with regard to other disfigurements. Indeed, future research should also examine the extent to which familial or cultural factors mediate the outcome of counselling and how this may contribute to the provision of counselling for vitiligo sufferers. As this was not examined in the present study, no comment can be made as to the extent to which these factors impacted the outcome of counselling. As mentioned, a strong motivation on the part of the client was required in order for the strict counselling protocol and homework regime to be adhered to, thus an investigation into the effects of counselling on a less motivated or committed sample needs to be considered when generalising from these results. Future research should also seek to examine the extent to which life stressors and psychological state are implicated in the progression of vitiligo. Further, when assessing lesion change with this patient group, photographs should be taken intermittently throughout the study to examine how quickly and at what stage re-pigmentation is initiated. As mentioned in the introduction, the selection of psychometric measures for assessing body, image, self-esteem and quality of life requires that various methodological and conceptual issues be taken into account so as to minimise the possibility of error. Although an attempt was made to take these factors into account, certain shortcomings which were inherent in the measures used, need to be addressed here. Firstly, questionnaires like the DLQI, BIATQ and the SIBID have a theoretical and conceptual bias towards negatively conceptualising

skin disease and body image disturbance. Therefore, this may have, to some extent, contributed to the results observed, although it should be noted that, this would have had an equal chance of affecting the results at all 3 assessment points, and since significant change was observed, then it is unlikely that this was an issue in the overall outcome.

Further, the questionnaires used, sought to measure how negatively a person feels about their condition, positive outcomes or feelings were only demonstrated by the absence of negativity. Therefore the positive aspects of skin disease were neither anticipated nor actively measured. Also in the case of DLQI it is noted that the average score of the present sample is significantly lower than the published norms for a dermatology population. The reason for this is that the questionnaire takes into account physical symptoms as well as psychosocial consequences of skin disease in assessing quality of life. Since the present sample lived with a condition with no physical symptoms (other than the depigmentation of skin) then this most likely accounts for the discrepancy. It should be noted that although quality of life was found to be higher for the vitiligo sample as compared to the dermatology norms, the sample's score was significantly lower than the general population, suggesting that it was able to elicit quality of life satisfaction.

As discussed earlier, the questionnaires used have established reliability and validity and therefore fulfil the practical and methodological requirements of

the study. Further, anecdotal observations of patient improvement are in accordance with the findings of the questionnaires underscoring the validity of using these measures for the present study.

The results of the present study will have implications in terms of our understanding of the role of mental state in vitiligo. The usefulness of this type of therapy may have implications for the management of different types of disfigurements as in the case of burns or traumatic injuries. The present study underscores the fact that the effects of dermatological disorders permeate much deeper than the skin. When treating patients with cutaneous illnesses, we must take into account the impact that these have on a person's self-esteem, quality of life and body image and seek to develop therapies which address these factors.

CHAPTER 6

Coping with the Disfiguring Effects of Vitiligo: A Preliminary Investigation into the Effects of Non-Directive Group Therapy

6.1 Chapter Summary

The experiment described in Chapter 5 yielded encouraging results with regard to the efficacy of Cognitive Behavioural Therapy (CBT) in counselling people with vitiligo. Participants made significant improvements in terms of increasing self esteem and improving body image and quality of life. However, one limitation of the study was that it was not possible to determine whether patients had benefited from the nature of the counselling protocol employed or whether the improvements they had made were simply the result of having the opportunity to discuss their feelings about vitiligo with someone who also had an interest in the condition. If the gains that participants had made in the earlier study were a product of the supportive counselling relationship and not the directive nature of the counselling approach, then subjects participating in a support group should yield similar gains. Therefore, a further experiment was conducted to examine the effect of a non-directive self-help approach on the same variables as in the first part of the study, namely self esteem, quality of life and body image, and at the same assessment times: pre-group; post-group; and at a five month follow-up.

The aim of this further study was to clarify what it was about the counselling process that brought about the positive changes observed in the first study. The results of this study suggest that there were no significant changes seen with regard to body image or quality of life, but that improvements were observed regarding self esteem. However, although patients improved on self esteem immediately following the termination of the group, these improvements were not maintained as indicated by the results at the 5 month follow-up. The implications of these findings are discussed and suggestions for future research are made.

6.2 An Overview of Support Groups

"…. a support group will comprise of somewhere between four and twelve people with a facilitator or leader. These people will usually share some common identified need and will have recognised the existence of that need such that they will be prepared to attend a relevant group as a possible means of dealing with the need. In addition these people will be capable of giving reciprocal care to other members of the group. The support group is about mutual help" (pp11, Nichols and Jenkins, 1991).

Counselling groups have become increasingly popular over the past 2 decades (Corey, 1995). One of the reasons for this is that they have been found to be effective in a variety of remits ranging from groups for hospital in-patients, to groups for professionals such as doctors and nurses. The effectiveness of groups is believed to stem from the fact that group members can benefit from the insight and feedback of other group members, and thus gain various different perspectives on a particular problem or issue which concerns them. Moreover, groups also offer many opportunities for modelling. Members can learn how to cope with particular situations by observing how others in similar situations cope. On a more practical level, groups are beneficial as they are more cost effective than individual counselling, since costs of running groups are lower and a broader distribution of therapists can be implemented (Yalom, 1995).

The strength of support groups, also known as self-help groups or helping groups, is centred around the act of bringing people together to create a

group environment and in turn group processes (Lakin, 1985). The sources of support which are derived from the group, come from group peers rather than the expert or leader within the group. The group members' presence, reactions and contributions are the basic resources of the group which will allow each member to build on and examine their own experiences and beliefs. The function of the group leader is to model, shape and preserve safety, the leader is a catalyst who can induce forward motion and change within the group (Nichols and Jenkins, 1991).

The basic mechanisms of the support group are group acceptance in return for self disclosure, mutual comparison, support and feedback (Lakin 1985). People often bring a powerful need to be accepted into their group, especially when in distress and in need of understanding from people who share their views. Individuals gain acceptance into groups when they begin to meet group objectives such as honest disclosure and exploration. Once members have acquired an understanding of group objectives and behaviours, then a self guided system is created (Yalom, 1995).

6.3 The Content of Support Groups

The basic notion of the support group is that exchanges between people, which promote self-awareness, will support individual members of the group and eventually promote forward motion and change. The way in which members exchange their thoughts and ideas will depend on the degree of safety which they feel, the life span of the group and the extent to which they are committed to making a non-defensive investment in the development of group life. According to the observations of Nichols and Jenkins (1991) this development will require members to learn to focus on issues of personal relevance rather than social rituals; to confront difficult issues; to self-disclose; to positively use the feedback and challenges of other group members in order to develop self awareness; to receive and give support and assist other members with these tasks. Each member of the group will differ in their ability to pursue these core interactions and initially, there may be a form of culture shock before members become accustomed to the rules of social interaction within these groups.

Support groups provide an alternative social structure where members can develop new self perceptions and new norms upon which they can base their self esteem. Individual members gain relief through processes such as confession, catharsis, mutual identification and reduced feelings of

stigmatisation. These group processes replace 'I' feelings with 'we' feelings thus giving the individual the sense of being in a group and redefining certain norms of behaviour (Lakin, 1985).

6.4 Self Help vs. Psychotherapy Groups

Although both seek to promote positive change and personal growth in a group environment, there are some critical differences between self help groups and psychotherapy groups (Riordan and Beggs, 1987). A basic difference involves the goals of the group. Support groups have as their central topic a single issue such as an addiction or health condition, whereas therapy groups have more generalised goals such as personal development or interpersonal functioning (Riordan and Beggs, 1987). Further, the nature of the leadership employed between these groups differs. In more structured therapy groups, group leaders are typically psychologists, psychiatrists or clinical social workers. In less structured support groups the 'group leader' (if one exists) is usually not a mental health professional and is often someone who has a special interest in the group or is has had personal experience around the central topic which the group discusses. Using a professional to guide the group is often deliberately avoided so as to maximise self reliance and the mutual aid of peers within the group (Telch and Telch, 1986).

6.5 The Use of Groups in Medical Contexts

In a recent review of the literature in this field Riordan and Beggs (1987) found that support groups played a significant role in the medical and rehabilitation arena. According to Meissen et al., (1991), the reductions in mental health services coupled with the growth of consumer movement, will make self help groups as important to the field of health as Alcoholics Anonymous (AA) and related groups have become to the field of substance abuse (Corey, 1995).

Support groups represent an important resource for the chronically ill. These groups are available for patients with various illness from stroke patients, patients recovering from myocardial infarction, AIDS and cancer patients. Members discuss issues of mutual concern that arise as a consequence of illness. They often provide specific information about how others have successfully dealt with problems raised by the illness and provide people with the opportunity to share their emotional responses with others facing similar problems (Gottlieb, 1988; Lieberman et al., 1979).

Potentially, social support groups can satisfy unmet needs for social support from family care givers. Alternatively, such support groups may act as an additional source of help by those going through the same event. The literature in this field suggests that chronically ill patients report a variety of

positive as well as negative experiences from such contacts. On the positive side, Taylor et al (1986) indicate that, in the cancer patient support group they examined, members found it very helpful to listen to other peoples stories and pattern their coping efforts on those members whom they identified as good role models. Further, patients in this study indicated that functioning as a role model was also very beneficial and served to enhance self esteem and a sense of control over the condition.

On the negative side, support groups reach only a small proportion of chronically ill patients (Anderson, 1988). They seem to appeal disproportionately to middle class, well educated white females and therefore the impact on these groups on a wider population is yet to be established. Furthermore, depending on how vocal or confident a particular group member is, he or she may not be given the opportunity to raise issues of personal concern or use the group time as constructively as other more confident or vocal members.

Studies in the field of medical support groups have tended to evaluate the efficacy of such groups by comparing group participants with those waiting to participate or non participants. The majority of these studies have found positive effects in the case of several illnesses including rheumatoid arthritis (Bradley at al., 1987) cancer (Telch and Telch, 1986) and cardiac disease (Dracup, 1985). There has even been some preliminary evidence to suggest that support groups can promote better health. In a study on the efficacy of

support groups in medical contexts, Spiegel et al., (1983) found that patients in a weekly cancer support group survived longer than their non-participant counterparts.

6.6 The Use of Group Counselling with Cutaneous Conditions

In the U.K. today, there are at least 20 self help groups set up for people with various dermatological illnesses ranging from life threatening disorders such as Dystrophic Epidermalysis to 'cosmetic' disorders such as nevus (port wine stains). The format of these support groups ranges from information giving and informal meetings, to structured support groups facilitated by mental health professionals. However, although there is much interest in providing people with access to these sorts of groups, little evidence exists as to their efficacy. Indeed the sparse literature which is available in this field tends to focus on the use of directive groups or psychotherapy groups, both of which tend to follow a structured format or agenda. Further, most of this research focuses on the alleviation of the cutaneous symptoms rather than the psychosocial effects of the support groups. For example, Cole et al., (1988), describe the use of group psychotherapy in treating eczema. In this study, ten adult eczema patients were given group psychotherapy as a supplement to their regular medical regime. The psychological treatment used was structured in its format and consisted of relaxation training, behavioural ratings and sensation discrimination amongst other things. Group therapy

proved useful, when compared to a control group which received only conventional medical treatment. Patients were able to reduce the targeted symptoms, but little reference was made to the psychosocial gains made by those involved in the study, nor do the authors comment on the efficacy of individual counselling in similar settings.

As well as examining the efficacy of group therapy in reducing target symptoms, literature in this field has also focused on the use of training in groups to improve social skills and social interaction. Robinson et al., (1996), describe one such case, where a group of facially disfigured people (with a range of disfigurements including burns, facial palsy and skin disease) attended a 2 day workshop on social skills training. A significant improvement was observed in terms of social anxiety, depression and social avoidance among participants 6 weeks following the workshop and at a 6 month follow-up. However, because of the structured, directive nature of this group, it is difficult to establish why participants made the gains they did. It may be that the people in this study improved because they had the chance to interact with other people who shared common life experiences and interests, and not because of the skills that they were taught in the workshop.

It is important to have an idea about what aspects of the therapeutic process are benefiting the patient when offering psychological interventions to people with cutaneous conditions. It may be that patients who experience the psychosocial difficulties which come with the disfiguring nature of skin disease

feel isolated, misunderstood and lonely. The opportunity to discuss one's condition with someone who has an understanding of this, or has had similar experiences may be so beneficial so as to be accountable for the positive changes observed in the previous study described in Chapter 4 and Robinson et al's (1996) study. Alternatively, it may be that the reason disfigured patients show improvements following counselling is less about supportive relationships and more to do with learning practical techniques such as coping with staring, or being able to restructure one's thinking to account for a new body image. The present study will attempt to address this issue by examining whether the positive effects observed in the previous study which used CBT, can be replicated with the use of a non-structured, non-directive support group.

6.7 Method

Participants

Participants were recruited through an advertisement in the U.K Vitiligo Society's[1] quarterly newsletter in August 1996. The inclusion criteria for participation required volunteers to:

- be over 18 years of age
- have been formally diagnosed by a dermatologist
- not have previously undergone or be currently undergoing counselling to help them cope with their condition
- have had the condition for at least one year
- not be taking any form of psychotropic medication.

16 people responded to the advertisement by writing to either the Vitiligo Society or the author. Of the 16 respondents, 1 was excluded from the study because she was under the age of 18. One week prior to the start of the study 5 volunteers withdrew. Three of the 5 indicated that the time commitment would be too strenuous if they were to be allocated to the treatment group. The other 2 indicated that they would be too self conscious to discuss their feelings in the presence of others and would therefore prefer to either be involved in individual counselling or withdraw from the study. This left a total of 10 volunteers who were matched for age, sex and ethnicity and were then randomly allocated to enter either the treatment group or the control group.

[1] The Vitiligo Society is a UK registered charity set up to provide information and support to people with the skin condition vitiligo.

The patients allocated to the treatment group received group counselling on a weekly basis over an eight week period. The sessions took place in one of the counselling rooms in the department of psychology at City University, London. Of the 10 participants who took part in the study, 7 were Caucasian, 2 were Indian, and 1 was Afro-European. There were 6 females and 4 males in the study, ages ranged between 29 and 63 with a mean age of 43.8. On the average, vitiligo had been diagnosed 21.1 years previously, with a range of 8 to 43 years. Of the 10 participants 8 were either married or cohabiting. Among the total sample, 9 participants had vitiligo on a visible part of their body such as hands and neck (see Table 10).

Table 10 **Sample Characteristics**

Sample	Control Group	Experimental Group	Total
Males	3	1	4
Females	2	4	6
Mean age	42.9	46.2	43.8
Asian	1	1	2
Black	0	1	1
White	4	3	7
Vitiligo years (mean)	18.5	22.3	14.2
Cohabiting with partner	4	4	8
Receiving PUVA treatment	2	0	2
Vitiligo visible when fully clothed	5	4	9

Design

The study employed a mixed 2x3 factorial design. The between-subjects factor was the treatment group: group counselling versus conventional treatment. The within-subjects factor was the assessment point: pre-treatment, post-treatment (directly following the counselling period) and a follow up at 5 months.

Instruments

The outcome measures used were a series of four standardized questionnaires. These were given to each participant to complete on three occasions: prior to therapy, immediately following therapy and 5 months following the last therapy session (See Appendix). The four questionnaires used were the same as those used in the preceding study which looked at the use of CBT with vitiligo patients, namely The Dermatological Life Quality Index (DLQI) (Finlay and Khan, 1992), the Rosenberg Self Esteem Scale (RSES) (Rosenberg, 1965), the Body Image Automatic Thoughts Questionnaire (BIATQ), (Cash, 1990) and the Situational Inventory of Body Image Dysphoria,(SIBID) (Cash,1993).

Participants were asked to have their photographs taken prior to and 5 months following counselling. However, of the 10 participants only 4 agreed to this, 3 from the experimental group and 1 from the control group. One of the members of the experimental group was not eligible to have her photograph taken since she was involved in a clinical trial of pseudo-catalayse treatment for her vitiligo. Due to the small number of participants who agreed to have their photos taken, it was decided that any changes observed would not be meaningful in light of the sample number and un-balanced ratio of treatment to control group members, and this part of the study was omitted.

Procedure

One and a half hourly group counselling sessions with a counselling psychologist were conducted weekly over an eight week period during the months of September and October. The format of the group was such that it was non directive allowing members to freely express their ideas and emotions regarding their condition. There was no set agenda between sessions, nor were members expected to disclose or share information if they did not so wish. Time was spent in the first session discussing with patients the format of the group. All members were assured of confidentiality and were told that the intention of the meetings was to provide a safe environment where people could discuss their feelings regarding vitiligo. Participants were told that there were no expectations regarding how much they spoke or what aspects of their experience they wanted to discuss. It was also explained to the volunteers that although a psychologist would be attending the sessions, that she had no set agenda of how the group should proceed and that her only expectation was that confidentiality and respect could exist among members. All members were asked to try to attend all 8 sessions, and to be as punctual as possible.

Once people had volunteered to be involved in the study, a detailed letter was sent to them outlining what the study would entail, and indicating that participants would be required to complete a series of questionnaires on three separate occasions.

Participants were sent the questionnaires through the post a week prior to the start of the study. They were given written instructions on how to complete the questionnaires and were asked to return them as soon as possible by post. Questionnaires were sent to all participants again at the end of the 8 week course of therapy and for the final time at 5 months following the end of therapy. Questionnaires were posted to all participants regardless of whether they had been allocated to the treatment or the control group. Along with the questionnaires, participants were sent a consent form which explained the nature of the study, assured patients of confidentiality and explained that they could withdraw from the study at any time if they so wished. A form was also included which outlined the importance of completing the questionnaires without the influence of others. Each questionnaire included clear information on how it should be completed.

6.8 Summary of group counselling sessions over the 8 week treatment period:

During the course of the eight week treatment period, only 3 of the 5 volunteers involved attended regularly. The other two volunteers missed 3 and 5 of the group sessions respectively, although neither of them withdrew from the group. Since there was no structured format followed in the sessions it is not possible to give a detailed outline of the weekly protocol of the sessions. However, a brief summary of what occurred in each of the sessions follows:

Session 1: Four members attended this session, three females and one male. One member, 'M', who had planned to attend called prior to the session indicating that she would not be able to attend until the following week. The rest of the group members, including the psychologist sat in a circle. Discussion was initiated by the psychologist who explained the ethos of the group. She indicated that there was no set agenda for the present session and nor would there be for any of the following sessions. She explained that the only expectation that she brought into the group was that members respect each others views, and keep confidential any issues raised

in the sessions. She also indicated that she would not be leading the group but rather, would act as another group member who had a personal interest in the condition. The psychologist also indicated how many sessions the group would last for and how long these would be. She asked if there were any questions members had regarding the group. All members indicated that this was clear and discussion was then initiated by the male member of the group 'H' who began to speak of the onset of his condition and how this made him feel. As he spoke, other members intervened to share their views on his experiences. Discussion for the remaining time in the group centred around how members felt when they first discovered vitiligo lesions and how they first came to hear about the term 'vitiligo'. There was also discussion around different treatments that members had tried and the efficacy of these treatments. The group also discussed the possibility of a cure being found for the condition and how this would impact their lives.

Session 2: Prior to the second session, one of the female members, the only Asian member in the group (R), contacted L.P and indicated that her car had broken down so that she could not make this weeks session but would attend the following week. The therapist opened the session by passing on R's apologies, and by introducing M who had missed the previous session. The discussion was once again initiated by H who began to speak of how difficult it was to loose his healthy golden colour, something that he had always taken a lot of pride in. The discussion was then picked up by M, the only Afro-Caribbean member of the group who began to speak about the implications of

loss of skin colour in dark skinned races. She spoke of the implications of losing her racial identity as her skin depigmented, and the difficulties she experienced around this. The discussion was then picked up by K, a white British woman in her late forties. She began to speak about how up until the age of 21 she had never seen a black person, and that she was quite shocked to find that even very dark skinned races could suffer with vitiligo. She asked M if she thought it was more difficult for her to cope with vitiligo because of her skin colour, and the discussion continued centring around race, culture and vitiligo.

Session 3: The third session was attended by four members M did not attend. K began the discussion by asking whether M had indicated why she would not be attending the session. L explained that she had not received a message from her but would let them all know in the next session if she spoke to her. H continued the discussion by telling R of what had been spoken about in the previous session that she had missed. R then began to speak of her experiences as an Asian woman with vitiligo. She indicated that she could have related to M in terms of how her vitiligo had affected her cultural and racial identity. She spoke of how she had been ostracised by many members of her community because of her condition and how it had also affected her relationship with her husband, who had rejected her since the onset of her condition. M explained the social significance that the majority of Asians she knew attached to vitiligo. She explained that in her

culture vitiligo was seen as punishment for some wrong doing that had been done either in this life or a previous one. She indicated that her experience of vitiligo was very much bound up with guilt and shame. Another female member C, picked up the discussion and indicated that although she was a white woman whose culture didn't overtly blame her for her condition, that she too felt ashamed of her changing appearance. She explained that as a woman, so much emphasis was put on looks and that this made vitiligo particularly hard to live with. H, the only male in the group, responded by speaking of his experience of vitiligo from a male perspective and the discussion then continued centring around the issue of gender and cultural differences.

Session 4: Discussion in this session was initiated by the therapist L, who indicated that she had been contacted by M who explained that she would not be able to attend for the next 3 weeks as an unexpected problem had arisen at her workplace that she would have to attend to. M had indicated that she was very sorry but that she would return to the group as soon as she could. The group discussed this and R indicated that she was sorry she had not yet had the chance to meet M as she would have liked to have discussed vitiligo with another dark skinned person. She indicated that on a practical level she would have liked to discuss camouflage make-up with another dark skinned vitiligo sufferer. K explained that she too had had difficulties finding realistic looking camouflage make-up, and other members began to speak of the

experiences they had had and give their views on different cosmetics. K then brought up the issue of treatment and began to speak of her experiences on a trial for a new vitiligo treatment, pseudocatalayse. Other members showed interest in this and the discussion was then centred around causes of vitiligo. H, indicated that he felt very strongly that his vitiligo had been the result of a very stressful period in his life. C indicated that she agreed with him and the group then began to share negative experiences they had had prior to the onset of the condition which they felt contributed to it. One of the members K became quite emotional during the session and shared with the group her experiences of the condition. Towards the end of the session the discussion began to centre around body image and self esteem, with various members discussing quite abusive and traumatic experiences they had undergone as a consequence of their altered appearance.

Session 5: Only three people arrived at this session, R and M did not attend and sent their apologies. C opened the discussion saying that she wanted to share a funny story about her young grand-daughter who had only recently noticed her vitiligo and had asked her if she had been finger painting with white paint. This prompted the other members to share there own family experiences with regard to vitiligo. One of the concerns that seemed to resonate across the group was that members feared that their children or other family members would acquire vitiligo and have to live with its consequences. H indicated that he felt that one of the most difficult aspects of the condition was having to live with the uncertainty about its progression.

C explained that in her opinion the most difficult thing about living with the condition was that it was not a private matter and that she resented all the questions, comments and stares that she would get from strangers. C also indicated how difficult it was to get support and understanding from doctors who would often dismiss the condition as nothing serious. K indicated that she too had often been made to feel guilty about worrying about her vitiligo and was actually told to stop wasting the doctors time. H indicated that as a male he felt it was even more difficult to talk about his condition and gain support from others since as a man he was expected to cope, and not worry about such 'cosmetic problems'. The remainder of the session was spent discussing how difficult it was to find people who could really understand the emotional and social effects of living with vitiligo. C indicated that she was finding the understanding that she got from the group very supportive and that she found it useful to speak to others who could relate to her and really understand what it was like to live with vitiligo. The other members said that they agreed and the rest of the session was spent discussing how important it was to make others understand the social consequences of vitiligo.

Session 6: Four members attended this session, M again was not able to attend. The discussion was opened by R who wanted to share an experience about a recent 'get together' she had attended. She indicated that she sometimes felt that vitiligo had affected her personality and the way she acted in front of others. She explained that others seemed to look at her differently

and did not want to associate with her because of her vitiligo. H asked if she thought that people were acting in strange ways towards her because she was expecting them to and in turn acting differently towards them. This initiated a discussion on expectations about how others perceived people with vitiligo and altered appearances in general. C indicated that although she had had several negative experiences with vitiligo, that she had noticed that when she wasn't thinking about her experience or feeling positive about herself, that others reacted more positively towards her. H indicated that he had also had similar experiences, but that unfortunately the experiences that stood out most for him were the negative ones. K indicated that she could relate to this, and that some of the negative things that had been said to her had very much affected the way she saw herself. The discussion for the remainder of the session continued centring around self esteem and body image.

Session 7: M attended for this session following a three week absence and R called to say that she could not attend as did H so there were 3 people involved in the group. M opened the discussion by apologising for not being able to attend the previous sessions. C gave a summary of what had been covered in the previous session and a discussion about body image ensued once again. M explained that in her family, she and the rest of the women

were quite strong and that vitiligo was not seen as much of an issue. She explained that she felt that her value lay not only in her appearance but more so in her intelligence and the relationships she had with her family and friends. K indicated that her perception of herself was very much bound with the way she looked and that this had stopped her from enjoying existing relationships and establishing new ones. She went on to explain that her low perception of herself, which she felt was caused by vitiligo, had made her avoid many public situations and activities. C indicated that she also felt that her self esteem had suffered because of the way she looked and that because she rarely had the opportunity to speak to others about her condition, she found that she got little support and understanding from those around her. The discussion then began to centre around how difficult it was to feel understood by others who had not had the experience of looking 'strange' or 'different'. The remainder of the session was spent discussing issues of belonging and feeling different within social groups.

Session 8: All of the group members attended this session except for M who called to say that she was very sorry that she could not attend and asked the therapist L to give her apologies to the group and to say goodbye to them. The discussion was opened by H, who started off by saying that he would miss the weekly meetings and the other members of the group. R agreed and indicated that it was a shame that the Vitiligo society did not offer ongoing support groups for people with vitiligo. C indicated that she had tried to organise 'get togethers' for vitiligo members in the past and asked whether

the other members would find it useful to meet on an informal basis. The discussion then began to centre around the issue of ending and how the group might find alternative ways of gaining support once it had ended. At the end of the session several members hugged, said goodbye and thanked the therapist and each other.

Summary

Over the course of the eight week counselling period, group members appeared to establish accepting relationships which allowed them to disclose information about themselves and their experiences with vitiligo. They were able to address a variety of topics ranging from practical issues such as diet and camouflage make-up, to more sensitive issues such as body image and self esteem. The members seemed relieved that they were able to speak to others who had had similar experiences to their own and who could understand the difficulties of coping with the condition.

However, there did seem to be a need, for the majority of the members, to have their story or view heard rather than to listen to that of others. It seemed as though for many members the group was the only place that they could vent their views and frustrations and that this need often overrode there ability to listen to others stories. The fact that the group was quite diverse both culturally and socially, appeared to make it more difficult for members to engage with others whose experience differed from their own. Indeed, the

fact that two of the members missed several of the meetings appeared to compound this disparity, influencing the way members engaged with each other, on several occasions there appeared to be a sense of resentment on the part of those who attended consistently towards those who did not.

Despite the fact that members had been told that the group would be run as a non directive support group, another difficulty which arose, particularly in the early sessions, was the expectation on the part of the group members that the psychologist would direct the sessions and provide 'tools' for how to cope with vitiligo. There seemed to be a need for a quick cure or a simple tool which would make coping with the condition easier. This perception was eventually dispelled, and the process of dispelling this view, served to give the group a dependence upon itself which appeared to enable members to become more self reliant and establish trust and confidence within the group.

Overall, the group appeared to make some progress in terms of supporting each other and discussing previously avoided or emotionally difficult topics. However, there seemed to be little in the way of challenging each others thoughts, with the exception of the only male participant 'H' who was skillful and sensitive at getting his fellow members to examine and challenge their views. The dynamics of being the only male and eldest member in the group put 'H' in the role of leader on several occasions, a view reflected by two of the other members during the session he was absent. Despite the difficulties of the group process, members indicated that they had found it useful and

several indicated that they would have been interested in being involved in a similar group in future.

All 5 members in the experimental group completed the questionnaires prior to and following counselling. A multivariate mixed analysis of variance (MANOVA) was carried out using SPSS, with time (within participants variable) and treatment (between participants variable) as the independent variables and self esteem, quality of life, body image automatic thoughts and situational body image as the dependent variables. No significant main effects of treatment or time were observed. However, univariate ANOVAs identified with MANOVA results indicated a significant improvement in self esteem for the treatment group ($F(7,11)=23.85$, $p<0.001$,).

There were no changes observed on any of the measures in the control group. There were significant differences found between the two groups following counselling on the self esteem index, and a significant improvement found within the experimental group, prior to and following counselling on this measure. However, this improvement did not appear to have been maintained at the 5-month follow-up, where scores indicated that participants

in the experimental group significantly decreased in self esteem (F (7,11)=24.00, p<0.001). No significant changes were observed in the control group at any of the three assessment points of the study Table 11 outlines the scores for each of the participants prior to and after treatment, and compares subjects scores with published norms of the 4 measures.

Table 11. **A Comparison Between Means Obtained From the Study and Published Norms**

Questionnaires	Norms		Pre-treatment results-control group		Pre-treatment results-treatment group		Post-treatment results-control group		Post-treatment results-treatment group	
	mean	s.d	mean	s.d	mean	s.d	mean	s.d	mean	s.d
[2]DLQI	24.2	20.09	12.00	3.00	13.20	7.16	11.80	1.48	12.60	5.37
SIBID	1.38	0.68	2.12	0.38	2.86	0.09	2.33	0.59	2.60	0.29
RSES	34.73	4.86	25.70	2.70	24.60	1.89	28.10	3.42	18.80	2.49
BIATQ positive thoughts	2.64	0.82	2.54	0.13	2.93	0.29	2.63	0.28	2.78	0.42
negative thoughts	1.80	0.63	2.92	0.26	2.99	0.34	3.02	0.35	3.03	0.40
ratio	0.41	0.11	0.65	0.03	0.61	0.01	0.65	0.05	0.63	0.04

[2] The norms given for this measure are derived from a population of dermatology patients and not healthy controls. The mean and s.d. given for a healthy controls with no skin conditions is 1.6 with an s.d of 3.5.

6.11 Discussion

The aim of the present study was to examine what effect a non-structured support group would have on self-esteem, body image and quality of life in vitiligo patients, and whether participation in such a group would yield the same results seen in the CBT study (See chapter 4). In agreement with other findings (Nichols and Jenkins, 1991), the results suggest that support group counselling had little effect on body image and quality of life but did help to improve the self esteem of patients with vitiligo. Nichols and Jenkins (1991) have noted that support is a product of group interaction, more so than in dyadic encounters and that through this, a participant feels lifted, empowered and strengthened and this will often have an impact on self esteem.

The improvements in self esteem were not sustained following the ending of the group. Perhaps the gains which patients made through attending the groups were in the relationships they formed with other members. Once the group came to an end, patients may once again have reverted to feeling the way they had prior to the start of therapy, especially if their own social support system was not very strong. This is supported by Lakin (1985) who suggests that feelings of loss and grief will often accompany the ending of a support group especially if members feel that they have not resolved all those issues which they brought with them to the group, and that many times smaller sub groups continue outside of the formal group environment between members

to mediate this loss. Further, since the therapy was not concerned with equipping members with tools they could use to cope with their condition, or with restructuring negative or inappropriate thinking, participants had nothing 'practical' to take away with them at the end of counselling. Thus they could not practice or rehearse those tools which they had found useful and in turn did not maintain the gains they had acquired.

There is evidence to suggest that the success of directive therapies like CBT lies partly in the practical tools that patients take away with them following therapy to help them cope with new difficulties as they arise (Garfield, 1994). The fact that no improvement was observed on any of the other measures suggests that improvements seen in the initial study were likely to be a product of the cognitive restructuring and directive nature of the counselling protocol employed and not merely the product of gaining support from, or speaking to, an interested party about vitiligo.

As in the case of the CBT study (Chapter 5), there were no significant differences found with regard to age, sex and ethnicity among the volunteers. Again, this is due to the fact that the in view of the small sample size it was not meaningfully possible to break down the sample further into sub-groups and test for these differences. Future research should seek to investigate the effects of sex, age and ethnicity with the use of a larger sample.

The results of the present study suggest that people can benefit from support groups in terms of improving self esteem but that the gains which patients make are not maintained beyond the end of therapy. Further, there is no indication that this type of therapy has any effect with regard to improving the body image or quality of life of vitiligo patients.

These findings will have implications for our understanding of the efficacy of counselling with this patient group. Interestingly, the number of people who volunteered for and actually attended all the group counselling sessions was actually much lower than those who volunteered for the individual therapy study (Chapter 5), where steady attendance was noted for all members. It may be that people with disfigurements are more wary of group situations in general and therefore less prone to enter into and engage in group therapy. It may be therefore, that this sort of therapy would have been more useful following a course of individual counselling where patients could first deal with some of these issues before entering what might be perceived as a daunting group situation. Future research should seek to address this. It may also be useful to examine the efficacy of such groups for people with varied disfigurements or skin diseases, since this might give more insight to members regarding different types of coping strategies used for different illnesses. The charity 'Changing Faces' has reported success with the groups it runs for disfigured individuals (Partridge, 1995).

In the previous study it was clear that patients not only improved, but that they were able to sustain improvements following the end of counselling. What was not clear were the reasons why patients had made and maintained these improvements. Although the results of the present study do not confirm what it was that instigated these changes, they do suggest that it was not the supportive counselling relationship *alone* that was responsible for these changes.

The counselling process is a complex system made up of many variables which contribute to the success and outcome of counselling. It is because of this that research in this area is so challenging to conduct, and why definitive outcomes are so hard to reach. Every attempt was made in both the counselling outcome studies described in this thesis to overcome difficulties in the internal and external validity of this type of research. Subjects were matched with controls in both groups, standardised measures for evaluating outcome were used, and selection biases were avoided. However, the study was not without its limitations. The small number of participants because of last minute drop-outs, coupled with high absentee rates meant that on several occasions the groups were extremely small, and therefore the views and experiences that were represented were limited. Although avoiding absenteeism and attrition is difficult it may have been more prudent to have had a larger sample originally to account for this. Further, the decision to run the group for 8 sessions was based solely on the fact that the previous study was run for 8 sessions and that the two needed to be comparable. The group

may have been more successful had it been run for more or for fewer sessions.

Despite the results obtained from this study, it is still difficult to conclude what brought about the changes observed in the outcome study described in Chapter 4. What we can say however, is that although the relationships we form within counselling are important, that when dealing with the trauma of disfigurement it is just as, if not more, important to equip patients with the practical and cognitive tools to face the challenges that arise from living with a disfigurement.

CHAPTER 7

Different Shades of Meaning: Exploring Illness Beliefs among Vitiligo Sufferers

7.1 Chapter Summary

One of the most interesting experiences of conducting therapy with a vitiligo population was listening to the interpretations that patients gave about their illness. These interpretations often contributed to negative thoughts that patients held about themselves and were voiced by patients in both counselling contexts. An important part of any counselling relationship is being able to empathise with the client and identify factors that may influence different forms of treatment. This is not always easy especially in cases where client and therapist do not share the same ethnic origin or culture. Indeed, such cultural *barriers* can affect patients beliefs about, and in turn adherence to, certain treatments, thus limiting the efficacy of care that can be offered to patients. Further, the episodic nature of vitiligo, coupled with a lack of a clear causal mechanism, means that sufferers have no established medical explanation for their condition. In the absence of a medical explanation sufferers may construct personal accounts of their illness that influence how the disorder affects them. This study explores the beliefs held by vitiligo sufferers about their condition, which act as a substitute for an established medical explanation. The Illness Perception Questionnaire (IPQ) was completed by 922 vitiligo sufferers.

Results suggest that illness perceptions vary according to race, age socio-economic status and the length of time a person has lived with the condition. There is also evidence to suggest that specific physiological symptoms such as sore eyes and headaches may be associated with the condition. The implications of the current findings are discussed and suggestions for future research are made.

7.2 Introduction

Conceptualising Illness

Most people are to a large extent uncertain about how their bodies work or how they become ill, despite the existence of the large knowledge base that exists in physiology and medicine. Even people who are well educated or those who have had their medical conditions explained to them in detail, may inaccurately conceptualise their condition (Biba ce and Walsh, 1979).

The onset of an illness can instigate a variety of problems, which can differ greatly from patient to patient even among people with the same condition. It has been suggested that when people gain information about their illness, that they integrate it into their existing framework or knowledge structure. In the case where this information is incompatible with what the person already believes about their condition, then this new information is often 'tailored' to make it fit. This of course can lead to erroneous conclusions or distorted interpretations about ones illness. It has been found that even conditions that are well understood medically, are not necessarily understood by patients (Lau and Hartman,1983; Petrie and Weinman, 1997). In a classic study by Biba ce and Walsh, (1979), the authors elicited illness beliefs about why people became ill, from a group of seven year olds, a group of college students and a group of biology major college students. They found that the group of biology

majors gave the same sort of explanations about their condition as did the non-biology majors. Indeed some of the reasons that both of the college groups gave for catching a cold were the same as those that the 7 year olds gave. Since it can be assumed that the biology majors had more knowledge about disease and physiology, then it can be postulated that their inability to describe disease mechanisms, reflects a difficulty in applying scientific knowledge at a personal level.

In a series of studies conducted by Howard Leventhal and his colleagues (Leventhal, Meyer and Nerenz, 1980; Leventhal, Nerenz and Steele, 1984; Meyer, Leventhal and Gutman, 1985; Leventhal and Diefenbach, 1991) the way in which people conceptualise illness was explored. Four components to the conceptualisation of illness were identified, namely, identity, timeline, consequence and cause. Lau et al. (1989) have indicted that patients' models also incorporate beliefs about the controllability and cure of their condition. These components provide frameworks through which illness can be interpreted and prototypical conceptions about illness. Based on these prototypical conceptions we formulate hypotheses about the meaning of our illness and seek information that confirms these beliefs (Bishop, 1990).

The psychological impact of meaning

The nature and extent of the psychological impact that the condition has on a particular person develops out of the meanings that the person attaches to the cause of their illness or condition. Patients' beliefs about how they have acquired an illness also directly influences their views about and attitudes towards treatment (Kleinman, 1988). Historically, the causes of disfigurement have been attributed to the wrath of gods, bestiality or penance for a past wrong-doing, though seldom through misfortune. These convictions can either facilitate or hinder coping (Cash, 1990).

Dermatological conditions, especially those which have a disfiguring component, are often surrounded by beliefs involving lack of hygiene and contagion (Whitlock, 1976). In cases of particularly stigmatising conditions such as leprosy, patients are believed to have acquired the condition as punishment for sins, and are therefore ostracised and shunned by those around them (Weiss et al., 1992). Other conditions such as facial acne are often believed to be caused by poor hygiene practices, and therefore the patient is sometimes thought to have caused the condition, thus evoking less sympathy and occasionally contempt from strangers or peers (Whitlock, 1976).

Weiss et al. (1992) found that there is a tendency in India to explain leprosy as having been caused by karma, guilt, punishment and malevolent influences.

The authors also found that in the case of vitiligo, diet, karma and guilt played a large part in patients' beliefs about the onset of their condition. Less stigmatising skin conditions such as tinea versicolor however, are more likely to be attributed to contamination by germs or uncleanness. Many of the illness meanings which patients give about leprosy and to a lesser extent vitiligo, are related to having acquired the condition as punishment for having sinned in the past. Stigma is often not confined to the affected individual but also to the patient's family or community. In the case of African-Americans, it has been suggested that vitiligo's impact was handicapping not only because of the stigmatising and disfiguring nature of the condition but also because the loss of pigmentation or 'turning white' may be conceived as a threat to racial identity (Porter and Beuf, 1994). In an earlier study, a predominantly Caucasian sample was questioned about their beliefs on what had caused their vitiligo (Porter et al., 1987). Respondents reported that either they or their family had caused the illness 'my mother had uremia during pregnancy', and held beliefs that the condition was genetic and therefore could be inherited by their children. It appears therefore, that significant variation exists across cultures about the cause and implications of vitiligo.

Gender has also been found to affect views and beliefs about illness. Numerous studies have concluded that women are more likely to consult their family doctor than are men (i.e. Nathanson, 1975; Cleary et al., 1982). Women are also more likely to seek medical help for cosmetic problems (Kleck and

Strenta, 1985). The gender discrepancy may be implicated in the different attributions that women and men give to health and illness. In a study on cultural and gender diversity on beliefs about the causes of six common illnesses, Klonoff and Landrine (1994), found that women were more likely than men to view a particular illness as being caused by sin and/or sex and as a form of punishment. Similarly, Robinson et al. (1996) found that disfigured females were significantly, although only just significantly, more depressed about their appearance than were their male counterparts and, may have been more likely to internalise feelings of stigmatisation.

Socio-economic status (SES) may also have an effect on illness beliefs and feelings of stigmatisation. In the United States for example, socio-economic status is strongly associated with ethnicity, gender and to a lesser degree, age. African-Americans and females tend to have a higher prevalence of low income and poverty than do white males. This in turn has tended to affect the attributions that these groups give to illness, and the way they interpret health promotion messages (Anderson and McNeilly, 1991). The caste or social class of the patient may also have some influence on the way that illness beliefs (Weiss, 1992).

An examination of the effects of age on self-concept revealed that appearance norms were stressed far less for the elderly than for younger populations, and that the elderly had developed more resources to cope with disorders which

affected appearance (Porter and Beuf, 1987). In accordance with this Cash, (1990) suggests that in later life, what is important for self image is not so much maintaining earlier body image features, but rather maintaining integrity, which is not necessarily dependent upon external appearance. This suggests that body image is a dynamic concept which is likely to vary according to age and life experience.

The present study uses the IPQ to try and solicit patients' perceptions about their vitiligo. The theoretical underpinnings from which the IPQ is derived are from the illness representation model (Leventhal, Meyer and Nerenz, 1980; Leventhal, Nerenz and Steele, 1984; Meyer, Leventhal and Gutman, 1985; Leventhal and Diefenbach, 1991; Lau et al., 1989), which identifies identity, timeline, consequences, cure and cause as the main components in the conceptualisation of illness. As discussed in Chapter 1, identifying and making sense of an illness will have implications on a person's beliefs about various facets of their condition. Drawing from what we know from the biopsychosocial perspective, these beliefs may in turn have not only a psychological affect on the patient but may also impact physiologically via the mechanisms described in Chapters 1 and 4. Since vitiligo has an uncertain aetiology then the labelling and in turn beliefs about timeline, treatment and outcome of the condition are likely to be based less on substantive medical knowledge and more on cognitive representations which the patient has developed. The IPQ

allows us to tap into these variables and gauge the extent to which illness representations vary according to factors such as race, age and sex.

Vitiligo is like a projective test, we have little medical knowledge about it, so people's views can only reflect lay medical models. It is hypothesised that illness representations are likely to vary according to demographic variables since it is through this 'demographic context' that we develop our beliefs about health and illness.

An 'ideal self' or 'ideal body image' is largely determined by the norms dictated by our gender, culture and age. An understanding of patients' views about the cause of vitiligo will help professional carers understand patients' attitudes towards treatment and care, and how they cope with the condition. Through this, health care professionals can incorporate patients beliefs into the care and treatment they are offered, thus improving the chances that patients will adhere to and benefit from these treatments. The present study examines how vitiligo patients understand the cause, course and outcome of vitiligo. An effort is made to explore how culture shapes illness beliefs and whether certain traits are more predictive of particular illness views than others.

7.3 Method

Participants

Questionnaires were sent to 1937 members of the UK Vitiligo Society, of whom 922 returned usable questionnaires. Respondents were over 18 years of age and had been formally diagnosed as having vitiligo by either their GP or dermatologist. Of the 922 respondents 289 (31%) were male, 633 (68%) were female, ages ranged between 18 and 69 with a median of 40-45. The median for the length of time respondents had suffered with vitiligo was 16 years with a range of 1 to 53 years. The majority of respondents were Caucasian (78%), 8% were Indian, 4% Pakistani, 2.5 % were Afro-Caribbean/European, 0.1% Japanese and 2% identified their race as 'other'. The most commonly reported religious preference was Protestant 34% and the majority of respondents had been educated to CSE/O'level standard (see table 12).

Table 12

Sample Characteristics

Males	31.5%
Females	68.5%
Mode of period diagnosed with vitiligo Range	16 years 1-53 years
Mode of Income Range	£10,000-15,000 £10,000-45,000
Mode of Education	CSE/O'Levels
Mode of Age Range	40-45 18-69
Pakistani	4%
Indian	8%
Afro-Caribbean/ European	2.5%
Japanese	0.1%
Caucasian	78%
Other race	2%
Muslim	6.2%
Hindu	5.9%
Protestant	33.9%
Catholic	8.0%
Bhuddist	0.4%
Christian Orthodox	14.4%
Jewish	3.1%
Other religion	6.0%
No religious preference	21.0%

Procedure

The UK Vitiligo Society was contacted in March 1997 and a request was made to enclose a brief questionnaire about illness beliefs with the Society's quarterly newsletter. After an examination of the questionnaire by the Council of the Society, it was agreed that the questionnaire would be sent out with the April 1997 newsletter. A letter was attached to the questionnaire explaining the purposes of the study. A reply paid envelope was provided with each questionnaire to facilitate a prompt response from members. Questionnaires received before July 1997 were included in the study.

Instruments

The Illness Perceptions Questionnaire (IPQ) (see Appendix 6) was the only measure used in the study (Weinman, 1994). This 38 item questionnaire, based on the illness representation theory, is made up of two separate sections. The first is concerned with what symptoms the respondents feel are associated with their illness, and comprises a 12 item symptom checklist. This section of the questionnaire has an internal consistency of α=0.82. The second part is made up of 26 items and deals with respondents' views about the control, cure (α=0.73), consequences (α=0.82,), the timeline (α=0.73,) and cause of their illness (Weinman et al., 1996).

The IPQ appears to have acceptable face and construct validity and has been found to be reliable as indicated by the scores on internal consistency measures given above (Weinman et al., 1996). All items in the first part of the questionnaire are scored on a four point Likert scale ranging from 1 'never' to 4 'all the time'. The second part of the questionnaire is scored on a five point Likert scale ranging 1 'strongly disagree' to 5 'strongly agree'. Patients were also sent a questionnaire requesting demographic information regarding age, sex, marital status and how long they had been formally diagnosed, by a dermatologist, with vitiligo.

Data Analysis

Data were analysed using SPSS for Windows. Each demographic variable was encoded as a 'dummy variable', so as to allow the analysis to be conducted with categorical data. A Principal Component Analysis (PA) was then carried out on the data obtained from section two of the questionnaire and a Stepwise Multiple Regression analysis was carried out between the demographic variables and each of the factors. Principal Component Analysis was also carried on the 'cause' sub-scale independently, and a multiple regression analysis was again carried out between the demographic variables and the factors derived from the sub-scale.

7.4 Results

An initial principal components analysis was conducted on the 26 illness perception questions of the questionnaire in order to set up dimensions along which the different demographic groups could vary. Minimum Eigenvalues were set at 1 and the Kaiser criterion was used to decide how many factors to retain. The Oblimin rotation was used in the analysis since an initial attempt with a Varimax solution revealed several variables that loaded on more than one factor. The principal components analysis revealed 6 factors, all of which were retained as they met the Kaiser criterion and because of their psychological coherence . Three items (16, 21, 24) were omitted from the data to increase the proportion of variance that was accounted for by the factors, which was found to be 63%. The lowest factor loadings and communality found were 0.518 and 0.488 respectively. According to Stevens (1992), the crucial factor in accepting a principle components solution is obtaining a mean communality greater than 0.60, in this case the mean communality was found to be 0.635 and therefore the analysis was deemed acceptable. Figure 5 outlines the 6 factors and the items associated with each. The factor loadings given for each solution are those derived from the pattern matrix as opposed to the structure matrix of the SPSS output. Stevens (1992) suggests that loadings from the pattern matrix indicate the importance of a variable to a factor with the influence of other variables partialled out, instead of the simple correlations

between factors and variables given by the structure matrix. The correlation matrix for the Oblimin rotation is given in Table 13.

Figure 5. Factors identified on the IPQ

Factor	Eigenvalue	Items	Communality	Factor loadings
1. perceptions regarding onset of vitiligo related to stress, costs and view of self and others	4.57	IP6- stress was a causal factor (+ve) ♦ IP7-illness due to my own behaviour(+ve) IP8-other people were a causal factor(+ve) IP10-my state of mind was a causal factor(+ve)	0.515 0.601 0.565 0.706	0.711 0.715 0.691 0.854
2. negative illness beliefs regarding severity, costs & view of self & others	3.15	IP14-serious condition(+ve) IP15- major consequences (+ve) IP17-not much effect (-ve) IP18-affected others view of me(+ve) IP19-economic consequences(+ve) IP20-affected how I see myself(+ve)	0.534 0.735 0.492 0.595 0.505 0.697	0.611 0.858 0.644 0.756 0.582 0.819
3. positive illness beliefs related to time and outcome	2.703	IP11- illness will last a short time(+ve) IP12- illness will be permanent (-ve) IP13-illness will last a long time (-ve)	0.568 0.758 0.762	0.614 0.887 0.894
4. positive beliefs regarding coping, treatment, symptom control & internal control	1.368	IP22- I can do alot to control symptoms(+ve) IP23- little can be done to improve illness IP26-my actions determine course of illness(+ve)	0.502 0.570 0.488	0.666 0.735 0.553
5. illness beliefs related to external causes	1.195	IP1-germ or virus caused my illness(+ve) IP2-diet was a causal factor(+ve) IP3-pollution was a causal factor(+ve) IP9-poor medical care causal factor(+ve)	0.605 0.589 0.612 0.597	0.798 0.518 0.754 0.512
6. illness beliefs related to chance and fate regarding onset & recovery	1.165	IP4-my illness is hereditary(-ve) IP5-it was by chance that I became ill(+ve) IP25-my recovery depends on chance/fate (+ve)	0.642 0.671 0.606	0.757 0.773 0.627

♦: the (+ve) and (-ve) signs denote agreement and disagreement with a particular item respectively

Table 13. Correlation Matrix for IPQ Principal Components Analysis

	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6
Factor 1	1.000					
Factor 2	0.203	1.000				
Factor 3	-0.213	0.060	1.000			
Factor 4	0.054	-0.105	-0.206	1.000		
Factor 5	0.356	0.165	-0.229	0.015	1.000	
Factor 6	0.050	-0.640	-0.084	-0.017	0.082	1.000

Once the data had been analysed, multiple regression analyses were carried out in order to examine how the demographic data gathered from the respondents was associated with each factor. The multiple correlations between the demographic variables and the factors were significantly different from zero (see table 14).

Table 14.

Results of multiple regression analyses carried out between demographic variables and factors

Factor	MULTIPLE-R	F	Signif. of F	Best Predictors	t	Signif. of t	β
1	0.411	3.92	<0.001	Jewish	-2.19	<0.05	-0.13
				Indian	4.36	<0.05	0.18
				Caucasian	3.23	<0.05	0.14
2	0.413	5.01	<0.001	Indian	2.95	<0.05	0.15
				Pakistani	4.34	<0.05	0.20
				living with vitiligo>10years	5.48	<0.001	0.15
				age (>45)	-2.21	<0.05	0.09
				income	-3.43	<0.001	-0.16
3	0.419	2.00	<0.05	undergraduate education	-2.43	<0.05	0.08
				postgraduate education	3.00	<0.05	0.10
4	0.405	1.39	<0.001	age(<25)	2.66	<0.05	0.10
				living with vitiligo<10years	-2.03	<0.05	-0.08
5	0.387	2.28	<0.01	Indian	3.74	<0.001	0.14
				Pakistani	3.10	<0.05	0.18
6	0.384	2.04	<0.001	post graduate education	-1.94	<0.05	-0.12
				Pakistani	-3.01	<0.001	-0.14
				Caucasian	3.45	<0.001	0.15

Scores on factor 1, 'perceptions regarding the onset of vitiligo related to stress, costs and view of self and others' were related to religion and race. The overall association was moderate (R^2 = 0.169) and the best single predictor was Indian (β=0.18). On factor 2, 'negative illness beliefs regarding severity costs and view of self and others' scores were related to race, age, length of time a person had lived with vitiligo and income. The overall association was found to be (R^2 = 0.171) and the best predictor was Pakistani (β=0.20). Factor 3, 'positive illness beliefs related to time and outcome' was related to education, with an overall association of (R^2 =0.176), and the best predictor being postgraduate education. The scores on factor 4, 'positive beliefs regarding coping, treatment, symptom control and internal control' were associated with age and the length of time a patient had lived with vitiligo (R^2 = 0.164) and the best single predictor was age (β=0.10). In the case of factor 5 'illness beliefs related to external causes' scores were associated with race (R^2= 0.15) and the best predictor was Pakistani (β=0.18). Finally on factor 6 'illness beliefs related to chance and fate regarding onset and recovery' scores were associated with education and race, the best predictor was Caucasian (β=0.15) and the association was moderate (R^2 = 0.147).

A further PCA was conducted in order to examine whether variables relating to *cause* would produce meaningful factors. The 10 variables in the questionnaire, which related to cause, produced 3 meaningful factors using

the Varimax rotation. The proportion of variance accounted for by the factors was found to be 64%. The lowest factor loadings and communality were 0.488 and 0.509 respectively, and the mean communality was found to be 0.602. Figure 6 outlines the 3 factors and the questions associated with each.

Figure 6 Causal Factors identified on the IPQ

Factor	Eigenvalue	Items	Communality	Factor loadings
1. internal causal beliefs	3.479	IP6-stress was a causal factor(+ve) ♦ IP7-own behaviour a causal factor(+ve) IP8-other people causal factor(-ve) IP10- state of mind causal factor(+ve)	0.509 0.594 0.502	0.709 0.720 0.689 0.835
2. external causal beliefs	1.293	IP2-diet was a causal factor(+ve) IP3-pollution was a causal factor(+ve) IP9-poor medical care a causal factor(+ve)	0.488 0.628 0.527	0.591 0.775 0.595
3. causal beliefs related to chance or fate	1.187	IP4-my illness is hereditary(-ve) IP5-my illness was due to chance(+ve)	0.696 0.629	0.806 0.746

♦: the (+ve) and (-ve) signs denote agreement and disagreement with a particular item respectively

As with the previous PCA, multiple regressions were carried out in order to examine how the demographic data gathered from the respondents was associated with each factor that was derived (see table 15).

Table 15.

Results of multiple regression analysis carried out between demographic variables and factors relating to cause

Factor	MULTIPLE-R	F	Signif. of F	Best Predictors	t	Signif. of t	β
1	0.37	4.09	<0.001	Caucasian Afro-Caribbean	3.48 1.89	<0.001 <0.001	0.14 0.13
2	0.41	1.23	<0.05	Indian Pakistani Muslim Hindu income	3.146 1.92 2.18 2.25 2.44	<0.001 <0.05 <0.05 <0.05 <0.001	0.12 0.09 0.11 0.14 0.10
3	0.39	2.01	<0.001	living with vitiligo>20years Jewish	-3.97 2.51	<0.001 <0.05	-0.14 0.08

Scores on factor 1 'causal beliefs related to internal causes such as stress and state of mind' were related to race, with Caucasian (β=0.14) being the best single predictor. The association was found to be (R^2 = 0.147).

Scores on factor 2 'causal beliefs related to external causes such as germs, diet and poor medical care' were related to race and religion, Hindu was the best predictor (β=0.14), and the association was found to be (R^2 =0.176). Finally, scores on factor 3 'causal beliefs related to chance or fate' were associated with the length of time a patient had lived with vitiligo,

and race, with the former being the best single predictor (β= -0.13). The association here was (R^2 =0.152). Details of these results including significance values are given in table 3.

Cognitive Representations

As mentioned previously the questionnaire used in the present study was based on the idea that patients develop internal cognitive representations of their condition, and that these representations have several elements including cause, consequences, timeline, cure and control (see Chapter 1). Interestingly, an examination of the initial PCA indicates that 5 of the 6 factors, which were derived, appear to cluster along these dimensions. All items loading onto Factor 1 (items 6,7,8,10) were related to cause; all items loading onto Factor 2 (items 14, 15, 17, 18, 19, 20) were related to consequences; items loading onto Factor 3 (11,12,13) were related to time; items associated with Factor 4 (22,23,26) related to control; and items related to cause (1,2,3,9) again loaded onto Factor 5. Factor 6 was a combination of items relating to cause (4,5) and cure (25). No comment can be made regarding how these dimensions varied on the second PCA since it included only those items related to cause.

Symptom Checklist

Although vitiligo is described by dermatologists as being symptom-less condition (Ortonne, 1997), respondents were asked to identify what symptoms *they felt* were associated with their vitiligo. The most commonly associated symptoms were identified as sore eyes (26%), sleep difficulties (24%) and fatigue (20%). Table 15 below gives a summary of each symptom and the percentage of respondents who felt it was implicated in their condition.

Table 16- **Percentage of Respondents Identifying Symptoms they Relate to Vitiligo**

Symptom	% of respondents identifying it as part of their condition
Sore Eyes	26%
Sleep Difficulties	24%
Fatigue	20%
Headaches	19%
Stiff Joints	18%
Pain	15%
Loss of Strength	14%
Upset Stomach	13%
Dizziness	11%
Breathlessness	10%
Nausea	6%
Weight Loss	4%

7.5 Discussion

The present study investigated beliefs held by vitiligo patients regarding their condition. The results indicate that there were considerable differences in how respondents perceived their illness and that these were related to the person's age, social, educational and cultural background. Interestingly, race seemed to override all other variables as a predictive factor including education and sex. Indeed certain variables which were anticipated to be significant predictors, such as sex, were not found to be related to any of the belief structure dimensions.

The results derived from the first PCA produced 6 distinct factors relating to perceptions of cost, consequences, duration, causality, and control. This is in accordance with the elements of cognitive representation model of illness (Leventhal et al., 1994; Lau et al, 1989). This suggests that the way in which patients arrived at an understanding of their condition was informed by the disease prototypes that they had developed and that new information that they gained about their vitiligo was being tailored to suit these prototypes. It is consequently not surprising, that race featured as the best predictive variable for most factors, since many of our ideas about health and illness develop early on in childhood and are to a great extent influenced by our cultural surroundings (Kleinman, 1988). In Latin folk-culture for example, common-sense beliefs about health and illness can be thought of as hot or cold. Arthritis, colds and stomach flu are 'cold' diseases and must be treated with 'hot' foods and medicines such garlic

and vitamins. 'Hot' diseases like rashes, need to be treated with cold foods and medicines such as coconut or aloe vera (Harwood, 1981). The discussion on race, below, further underscores this point.

The second PCA, which was carried out on just those items related to causality, produced 3 distinct factors relating to internal causes, external causes and chance. These factors are similar to those proposed by Wallston et al., (1978) in relation to the health locus of control scale (HLOC). This scale was developed to examine how locus of control (Rotter, 1966) was related to decisions and beliefs centring around health and illness. As in the case of the IPQ three types of HLOC were identified, internal, external (or powerful others) and chance or fate. This suggests that the factors obtained from the second PCA are connected to locus of control as it relates to beliefs about causality. Interestingly factors 5 and 6 on the first questionnaire were almost identical to factors 2 and 3 on the second, suggesting that beliefs about causality related to external causes and chance were very prominent in the sample.

Race

Race seemed to feature quite prominently as a predictive variable on many of the factors, in particular to those relating to cause. Indeed it featured as the best predictor on factors 1,2,5 and 6 on the first PCA and on factor 1 on the second analysis. The Indian and Pakistani population of the sample appeared to be more negative about their condition than other races both with regard to how they perceived themselves and how others perceived them. At first glance this is not surprising since the condition is likely to be more salient on darker skinned populations and therefore cause more body image disturbances. One would therefore expect similar results from the Afro-Caribbean/European sample, but this was not the case. A more culturally bound explanation may therefore exist for this finding. In their 1995 Annual Report the Vitiligo Society indicated that significance of vitiligo was of particular relevance to the Asian population explaining that the stigmatising effects of the condition often affected the whole family and that this had implications for the marital prospects of the sufferer. In accordance with this, Weiss (1992), reported that amongst Indians, vitiligo was often seen to be a karmic punishment for a past wrongdoing or as a result of a curse, thus increasing the stigmatising nature of the condition. The results of the present study resonate with this, with both Indians and Pakistanis indicating that other people and 'state of mind' played a role in the onset of their condition.

Another very common reason given for the onset of vitiligo by this population was that of diet. In a review of the historical descriptions of vitiligo, a reference to the condition dating back to 800 BC suggested that it was caused by the consumption of white coloured food, especially milk and fish (Svrivastava, 1994). An examination of the literature from India, revealed that diet, in particular malnutrition and vitamin deficiency, is believed to play a role in the onset of vitiligo, particularly in children. A study of 2000 newly diagnosed vitiligo patients showed that 34% had developed the disease before the age of ten and their records showed that a large number of the children had some degree of malnutrition or had consumed food high in preservatives and additives. The author states that "some noxious melanocyte destroying chemical entering the body through diet... might be an important factor in the precipitation of vitiligo in a susceptible host" (p. 31). The immunological balance is disturbed thus making the patient more likely to develop vitiligo. However, since no control group was employed it is possible that a similar proportion of malnutritioned children never develop vitiligo, or develop other conditions. The Asian population of the sample, tended to be more fatalistic in their view as to the outcome of their illness indicating that recovery was largely due to chance or fate. Again, drawing from the idea of karma, and superstition which seem to feature prominently in both the Pakistani and Indian cultures (Weiss, 1992) it is not surprising that beliefs around recovery centre around fate and destiny.

In the case of Caucasians, the largest racial sample in the group, respondent's beliefs about the onset of the condition centred around stress and heredity. The latter finding is in agreement with the results of Porter et al's. (1987) study which also found that heredity featured prominently in their sample as a causal explanation for vitiligo. A possible reason for this finding, is that in recent years, Western culture has turned to genetics as a means of explaining a whole host of conditions ranging from Down's syndrome to certain types of cancer (Radley, 1994). Prenatal and genetic screening has made it possible for prospective parents to reduce the chances of various illness, and terms such as DNA have become commonplace in our vocabulary. Therefore the concept of heredity has been integrated into our view of health and illness and serves as a basis for our understanding of why we get ill. Similarly the idea that stress is at the core of many illnesses has also been perpetuated by recent government health promotion ads. It is not unlikely therefore, that people exposed to this type of information might assume that stress is implicated in their illness. This is in accordance with Al' Abadie et al's. (1994) study, which found that psoriasis patients were likely to attribute the cause or exacerbation of their condition to psychological stress.

The Afro-Caribbean/European sample also attributed internal causes such as stress to the onset of their condition. They also appeared to be negative about their vitiligo with regard to how it had affected their perception of themselves but interestingly, this view was not found to be significantly more negative than other races. This result was unexpected

since vitiligo is more salient on darker skinned populations so a significant difference in perceptions about the condition would have been expected between white and dark skinned respondents. Interestingly, in agreement with these findings, is a study which examined responses of vitiligo patients to cosmetic disfigurement. No difference in adjustment or feelings of stigmatisation were found with regard to race between black and white patients (Porter et al., 1987). A later study which examined the effect of racially consonant medical contexts on adjustment of African-American vitiligo patients (Porter et al., 1994) found that support from people from one's own culture was a critical factor in adjustment to the condition. The study found that those patients who were seen in predominantly black hospitals with African-American physicians and staff, had less negative emotions associated with their vitiligo than their counterparts who had been seen in predominantly 'white areas'. It may be therefore that the Afro-Caribbean/European population of the present sample were also gaining support from their community and this in turn positively impacted their view of their condition.

Religion

Religion was found to be a strong predictor along several dimensions, and the best predictor for factor 2 in the second PCA. There seemed to be a predictive effect with regard to perceptions about beliefs patients held about themselves and others, as well as perceptions related to the severity, cost and onset of illness. Respondents who had identified

themselves as Jewish appeared to have better adjusted to the condition indicating that they did not feel that vitiligo had changed the way they perceived themselves or how others perceived them, and that it had not had severe consequences on their life. They were inclined not to associate stress as part of their condition, participants indicating that chance or fate were implicated in the cause of their vitiligo. The Muslim and Hindu group identified state of mind, others and diet as causal factors.

Age & Length of Time Living With Vitiligo

Age was the single best predictor for factor 1 and the length of time a person had lived with vitiligo was the best predictor for factor 3 of the second PCA. On all but one case, the age of the respondent and the length of time that they had lived with vitiligo were often predictive of similar illness beliefs. This is most likely due to the fact that respondents' age and the length of time they had lived with the condition was directly proportional, thus older respondent's had lived with vitiligo for a longer time. Respondents that had lived with their condition for an extended period of time, over 20 years, and the older members of the sample, were more positive about their illness and less likely to feel that it had negatively affected their lives. They were also less likely to identify stress or state of mind as a cause for their condition, and did not believe they could effectively control the course of their vitiligo. In accordance with this, the length of time a person had lived with vitiligo appeared to be implicated in

their beliefs regarding causality. The results of the second factor analysis suggested that patients who had lived with their vitiligo for longer than 20 years were more likely to attribute their condition to chance or fate.

Perhaps it is not surprising that the older members of the group had noted that vitiligo had not had major consequences upon their life. It is likely that these respondents were in a stable relationship and had established stable friendships, and therefore were less likely to have as much stress as younger respondents about meeting new people. In accordance with this Behre (1981), who examined the psychological effects of leprosy, found that psychological disturbance was much more profound in younger populations and in newly diagnosed populations than in older leprosy patients, and those that had lived with leprosy over an extended period. The author indicated that as they got older, patients adopted coping strategies, improved social skills and learned to accommodate problems related to their disfigurement.

Income

Those respondents at the lower end of the earning spectrum appeared to be more negative than higher earning respondents about their condition especially concerning how it had affected their perception of themselves. It may be the case that people whose incomes were higher also enjoyed more job satisfaction and therefore their self image was dictated not only by their external appearance but also by career achievements and

prospects. It may be that higher earners were more likely to be complimented on and respected for their work and thus the focus may have been taken away from their appearance by comparison with people in less skilled employment. Further, it appeared that lower income respondents had different perceptions about the onset of their condition compared to respondents from the middle and higher end of the income spectrum, who believed that diet was the most probable reason for the onset of the illness. It may be that people from less affluent environments had experiences with other illnesses being caused by poor diet or poor hygiene, and thus attributed vitiligo to these sources.

Education

Education featured in two factors and was the most significant predictor in factor 4. Respondents who had more formal education appeared to be more negative about the duration of their illness than those who had less formal education. Further, they were more likely to attribute heredity as the main cause of their vitiligo rather than chance as in the case of those respondents with less formal education. It may be that those with more formal education were more comfortable researching information about vitiligo, and therefore had more access to information regarding its course. It is also possible that those with more formal education were more confident about asking GPs and dermatologists about their condition and thus had acquired more information about vitiligo.

Sex

Surprisingly, the sex of the respondent did not appear to affect the extent to which they identified with particular illness views. A common lay view which has been supported by some empirical evidence (Cash, 1986; 1990) is that females are more conscious about their appearance than are males, and would therefore be expected to have more pessimistic or negative views about vitiligo. However, a review of the disability literature suggests that this is not necessarily the case.

In their examination of responses to disfigurement in self and others, Kleck and Strenta (1985), presented a group of adults with facial images of themselves that were normal or that had been manipulated to give the appearance of a facial scar. These images were shown in sequence with both the normal and disfigured faces of others. The authors found that no gender differences existed with regard to the nature or severity of the negative social implications that subjects projected for facial scars in themselves or others. In accordance with this, in their study on racial variation and degree of disturbance in vitiligo patients, Porter and Beuf (1992) found no difference with regard to the degree of disturbance in the case of gender, in either black or white populations. It may be therefore, that the assumption that females are more distressed by impaired appearance than males, is unfounded in the case of objective disfigurement.

Symptom Checklist

The results from the symptom checklist were unanticipated since vitiligo is believed to be a symptomless condition. The four most commonly reported symptoms were sore eyes, sleep difficulties, headaches and fatigue. Two of these symptoms, sleeplessness and fatigue, are also identified in the DSMIV as being indicative of depression (APA, 1992). It may be therefore, that what respondents were actually describing were symptoms of lowered mood or depression that could be attributed to emotional effects caused by the disfiguring nature of vitiligo. The most surprising result however, was that the most commonly identified symptom was sore eyes. More than 1 in 4 of all the respondents indicated that this was a symptom commonly associated with their condition. Indeed, these figures did not appear to vary with relation to age, race, religion, income, length of time living with vitiligo, education or sex. In all cases sore eyes featured in the top three symptoms indicated by all groups.

Several possible explanations exist for this finding. Firstly, it is possible that respondents were on some sort of medication for their condition that had side effects which affected their eyes. PUVA (psoralens + UVA light) therapy for example is designed to make the skin more photosensitive. It may be that it is also making patients eyes more photosensitive and that this is responsible for the pain that respondents are reporting. In a recent article which discussed the potential for PUVA to cause long term ocular

damage (See and Weller, 1993) it was suggested that although in some cases cataract formation had occurred after prolonged PUVA treatment, that this was generally quite rare and that following certain 'safety guidelines' would protect patients from complications related to this treatment.

Another possible explanation is that the vitiligo itself may be the cause of the sore eyes that respondents reported. A review of the literature on vitiligo makes few references to its effects on the eyes. However a condition known as Vogt-Koyanagi-Harada syndrome (VKH) has been associated with vitiligo in several studies (i.e. Trebini, et al., 1991; Okada et al., 1996) . VKH is a rare condition which is believed to have a cell mediated auto-immune pathogenesis, and is associated with poliosis, vitiligo, alopecia and neurological disorders, most commonly meningo-encephalitis. Initially it begins with ocular pain, reddening and photophobia. In severe cases it can lead to profound loss of vision. This condition has been found to be much more common in Oriental populations than in Caucasian populations, the chances of it being responsible for the eye pain that respondents report therefore are probably quite slim given the racial distribution of the sample.

One of the few clinical studies which examined the affect of vitiligo on the eyes was that of Smith et al., (1994), which looked at the retinoid-binding protein in the eyes of vitiligo mutant mice. The authors found that these mice demonstrated a slowly progressing retinal degeneration characterised

by the gradual loss of photoreceptor cells, and an uneven pigmentation of the retinal pigment epithelium. The authors indicate that this is the first study to provide evidence for altered retinoid metabolism in vitiligo mice and that further research is required in this area.

Another possible explanation for the 'sore eyes' that patients report may be that as in the case of other skin conditions such as eczema, the constitution of the tear may be changing, causing pain and discomfort (Berkow, 1992). Finally, it may be that it is not only the skin which depigments in vitiligo patients, but that their eyes also experience some form of destruction to the melanocytes. In the case of Albino patients, pathology of the eye is common (Okada et al., 1996), it is possible therefore that a similar mechanism is acting in the case of vitiligo. The headaches reported by respondents are likely to be associated with sore eyes since these are often implicated in ocular diseases (Berkow, 1992).

Although the results of the present chapter have answered several questions, they have also generated many others which future research should seek to address. The fact that males and females did not differ in their views on vitiligo should be examined in more detail, it is likely that in this case because the participants were obtained from the same source, that one would expect a symmetry regarding beliefs. It may also be the case that the location of the lesions have differing effects on the sexes. It is also possible that the more common use of camouflage make-up in females (Porter et al., 1992) is a mediating factor in women's views on the

effects of the condition. Future research should also seek to examine whether people who had identified themselves as non-British were first or second generation immigrants in Britain and how this may have impacted upon their views on vitiligo. The effects of family and social support on a patient's illness beliefs should also be addressed, and in particular how patients with other family members with vitiligo view their illness. Since the present study relied on a questionnaire to gather data, the depth of the information obtained was minimal. It would be useful therefore if different research methods such as in depth interviews or focus groups be used in future, to gain a more detailed picture of the results already obtained.

Examining patients' views on illness is a challenging task and although the present study attempted to overcome many of the difficulties associated with this type of research, it was not without its limitations. Firstly, the questionnaire was written in English, thus eliminating the possibility of gathering views from respondents who did not speak the language. Indeed, the fact that foreign patients who answered did speak English may have affected their cultural view of their condition, or impacted on the semantic meanings attached to each belief presented in the questionnaire. Secondly, the perceptions or concepts presented to patients were certainly not exhaustive of the many possible beliefs that they could hold about their condition. Thus the study limited respondents' views to only those that had been generated by the questionnaire. Furthermore, as mentioned earlier, the mode of data gathering combined with the large amount of respondents, limited the depth of the information that could be

accumulated. Therefore, many of the conclusions reached need further investigation if a truly in depth exploratory analysis is to be conducted. Indeed, much of the early research in the area of illness beliefs was obtained during in-depth or semi-structured interviews with patients (Leventhal and Nerez, 1985). This provides qualitative information which provides a deeper understanding of a person's representations and experience of their illness. However, the practicalities of producing such data including the issue of time and cost, severely limits the sample size of most qualitative studies. Given the very large size of the present sample a qualitative analysis would have been virtually impossible. Recent literature on illness perceptions has debated the utility of different methodologies, ranging from structured interviews to theory based questionnaires, used to measure cognitions (Conner and Norman, 1998; Petrie and Weinman, 1997). Some authors (Scharloo and Kaptein, 1997) have suggested that there is a need to study the relationships between the different dimensions of the illness representation model, others have suggested both interview and questionnaire research formats are guilty of over-lapping the dimensions of *timeline* and *consequence (Tennen et al., 1992)*. Since however, this area of research is relatively new, no 'perfect' measure of illness cognitions has yet emerged, there is a need therefore, for future studies to compare the reliability and validity of different methods, and assess their utility with different populations (Petrie and Weinman, 1997).

The findings of the present study will have implications for our understanding of how people with vitiligo view their condition. This should

be considered in the wider context of medical and psychological care of the vitiligo patient. It has been suggested that patients are more likely to comply with treatment if they understand and agree with the reasons that their physician gives for their illness (Kleinman, 1988). It is important therefore that physicians take their patients' beliefs about vitiligo into consideration and address them. With regard to counselling, it is imperative that the therapist can empathise with, and understand, their client's views on illness. Through this they can work together and re-assign negative illness meanings that cause patients to feel stigmatised and inferior. Furthermore, an understanding of a patient's illness beliefs will alert therapists to possible emotional or psychological problems, which may be associated with their condition. The present study has underscored the fact that beliefs about vitiligo can vary dramatically depending on culture, age and SES.

In most cases an examination of illness beliefs is undertaken to predict the uptake of, or adherence to, health behaviours and treatment regimes. This was not the case here; since vitiligo has no established cause or treatment, what we were interested in was understanding how patients conceptualise their disorder, not how well the IPQ predicts the health behaviours of this sample. An understanding of this conceptualisation would allow us to make assumptions about the psychological and emotional effects that vitiligo has on patients and how these effects vary according to socio-demographic variables. The results underscore the notion that a patient's representation of their illness is dependant upon these variables and illness

representations reflect cognitive and emotional responses to a patient's symptoms and illness in general. This is in accordance with Leventhal et al., (1984) who suggest that cognitive and emotional responses are processed in relation to illness representations. If the results of the present study are considered in light of the findings of chapters 5 and 6, there may be further evidence to suggest that the efficacy of psychological therapies to treat the effects of vitiligo lies to a lesser extent in the non-judgmental environment of the counselling relationship and more so in examining and challenging patient's thoughts and beliefs. This can serve to change maladaptive schemata that patients have formed about their condition and in turn affect their emotional responses to it. Further, as Conner and Norman (1998) suggest, where illness cognitions are causally related to health behaviours, then changing these cognitions should lead to positive behavioural changes and in turn, to more adaptive responses to the illness in question.

It is vital that as health professionals, the views that our patients hold about illness are respected and taken into account. It is only when we are able to understand our patients' fears, pain and hopes that we can help them, through their own experience, to move towards holistic recovery.

CHAPTER 8

CONCLUSIONS

8.1 Hypotheses

Four main hypotheses were posited at the beginning of the thesis. The first of these predicted that newly diagnosed vitiligo patients experience a higher proportion of stressful life events in the year preceding the onset of their condition than a matched clinical sample. The results of the study suggest that vitiligo patients had a higher proportion of stressful life events than their matched clinical counterparts. It was therefore postulated that if psychological variables contribute to the onset of vitiligo, then the progression of the condition might also be affected by psychological variables.

Therefore, the next hypothesis was that psychological counselling using cognitive behaviour therapy (CBT) would help to improve the body image, self esteem and quality of life of vitiligo patients and might impact the progression of the condition. Interestingly, CBT was found to improve body image, quality of and self esteem, even more interestingly, there also appeared to be an effect on the progression of the condition. In order to examine whether it was the counselling relationship itself, or the directive nature of the protocol used that helped clients make the improvements

observed, a third hypothesis was postulated, namely that being involved in a non-directive support group will help to improve the body image, self esteem and quality of life of vitiligo patients. The findings of this study were disappointing. Patients made limited improvements on only one of the measures, and these improvements were temporary. This suggested therefore, that it was not merely having the opportunity to discuss one's condition that was responsible for the improvements observed in the first outcome study, but was more likely a product of the cognitive and practical tools that patients gained from the CBT protocol employed.

The fourth hypothesis developed out of the narratives that people relayed about their condition in both the CBT and self-help groups. There appeared to be a need for patients to give meanings to the condition regarding its onset, course and outcome. Therefore the fourth and final hypothesis stated that variation would exist across vitiligo patients regarding their beliefs about the onset, course and symptomatology of their condition and that this would vary according to demographic variables. Results suggested that there was considerable variation across patients regarding their beliefs about vitiligo and that these beliefs appeared to cluster according to age, race and socio-economic status, among other variables.

8.2 Limitations

Although the limitations of each of the studies were discussed individually at the end of each chapter, a brief overview of some of the main limitations that are inherent to counselling research will be outlined here.

One such limitation is selection bias. This occurs when the method of allocating people to treatment and control groups is not random but introduces a systematic bias. This limitation was overcome in the experiments described in chapters 5 and 6, by randomly allocating patients to the control or experimental groups. However, the fact that patients were self-selecting, that is, they volunteered to be involved in the studies, introduces a form of bias into the results. Further, the fact that counselling was only offered in London, and conducted only in English precluded many possible candidates from taking part, again exposing the data to possible bias. Unfortunately, however, limitations such as these are difficult to overcome. Counselling can not be forced upon people, and it is extremely difficult to offer counselling on a weekly basis to people living long distances from each other. Therefore, the likelihood of avoiding this type of bias was minimised within the realistic constraints of designing outcome research.

Differential attrition rates are another difficulty, in conducting outcome studies. One can never ensure that a participant taking part in a study will be there until its completion. Illness, death, boredom and hassle are all factors, which can contribute to high attrition rates. This was one of the main problems in the study described in chapter 5. However, even in retrospect, there is not much more that could have been done to ensure that participants did not 'drop out'. All participants were given details about the length of the group meetings and what they would entail, and were given the opportunity to asks questions about the study before its commencement. This was done so as to ensure that clients understood the commitment of being involved in the study. However, the size of the experimental sample was significantly smaller at the end of the study than it was in the beginning, and this inevitably had an effect on the results.

A possible threat to external validity may have been the reactivity of the experimental arrangements, that is, the fact that they are participating in a study may influence the way in which clients or counsellors behave. Patients who are less motivated, or indeed counsellors who are not committed to a particular therapeutic model, may have obtained very different results in this case. However, the majority of patients who attended for counselling acknowledge that their commitment is a fundamental part of the therapeutic process. Similarly, counsellors will rarely use models that they do not have faith in, suggesting that the results

found in the studies are likely to be generalizable outside the experimental context.

Another limitation that was identified was the fact that patients questioned for the study described in chapter 7 were all recruited from the same source, the Vitiligo Society. It is possible therefore that a biased view of the vitiligo sufferers beliefs was being tapped into. Patients involved in the Society may have all shared a common view about the condition which may have prompted them to join the Society. Unfortunately, the large sample required for this study would have not been obtained as readily using other sources for recruiting. Further, the fact that the respondent rate was so high, suggests that sufficient variation existed between patients in order to obtain the results that the study yielded.

There was an attempt to expel the effects of all of the limitations described. However, the reality of research sometimes only permits us to minimise these effects and to cautiously interpret data in light of these. Therefore, although there were flaws identified in all studies, these were *controlled* for as much as possible, within the inherent restrictions of conducting experimental research.

8.3 Themes

Taking a systemic view of the patient

The studies described in the present thesis were constructed within a biopsychosocial framework. There has been an attempt throughout the thesis to underscore the reciprocal relationship between the skin and the psyche and to emphasise the psychological dimension of skin disease. It is not clear that vitiligo develops or indeed progresses dependent of psychosocial stimuli. There appears to be an 'interdependent' relationship between the skin and the psyche, and the findings from these studies consistently suggest that the impact of skin disease affects many different areas of peoples lives such as body image, self esteem and quality of life. Similarly, there is at least preliminary evidence to suggest that vitiligo can be affected by a person's psychological state. These findings indicate that vitiligo can be viewed from a biopsychosocial perspective, rather than attempting to conceptualise this condition as a discrete medical problem. By taking into account the subjective experience of the vitiligo sufferer issues, such as body image, self-esteem, and quality of life can be addressed, which are fundamental aspects of the patients experience,. The focus can then be taken away from the vitiligo as an illness and be put on the vitiligo sufferer as a person.

Illness Representation Models

In recent years much interest has centred around the usefulness of illness representation models (e.g. Tennen, 1992; Bagozzi, 1993; Conner and Norman, 1998; Petrie and Weinman, 1997). The use of cognitive illness representation models in health and counselling research offers a number of advantages. Firstly, they are based on a clear theoretical background, providing researchers with distinct variables to measure. Secondly, they are able to identify variables, which are important in predicting health outcomes, and in turn enable the development of effective interventions in both health promotion and medical counselling. Thirdly, these models describe the thought processes involved in motivational factors relating to health behaviours. Like most theories, which attempt to explain behaviour and motivation however, cognitive representation models are not without their difficulties. In a recent work by Conner and Norman (1998), the authors indicate that although the clear, theoretical framework provided by illness cognition models is useful, that it might lead to the omission of other variables such as emotions and complex interpersonal interactions, that may be important in understanding health behaviour. Secondly, while these models highlight potential areas where intervention is needed, they do not indicate how these interventions should work and how cognitions are best changed. Finally although illness representation models contribute to our understanding of motivational processes, they tend to neglect other aspects of behaviour change (Bagozzi, 1993). Future

research needs to address these issues and studies using these models need to acknowledge such criticisms.

Examining the Cognitive Illness Representations of Patients

A theme that resonated throughout the thesis was the idea that patient's beliefs had a significant effect on the way they conceptualised and coped with their condition. That is, there appeared to be a 'two-way' relationship between illness experience and ideas about illness i.e. experience of illness as mediated through cognitions and cognitions about illness modified by experience. In chapter 5, the study which examined the effects of CBT on patients with vitiligo, there was evidence to suggest that the negative thoughts which patients held, were significant indicators of adjustment. The fact that participants were able to learn to identify and challenge irrational or negative beliefs about their vitiligo and the effects it had on them, allowed them to deal with their condition more effectively. Further, in certain cases, the patients who took part in the CBT and Group Therapy studies, had constructed causal ideas about their condition which included guilt or shame about a certain action for which they felt that they were being punished. In these cases, manifestations of the condition, such as spreading of the lesions or encountering difficult social situations, were

internalised and modified to conform to these negative constructions (see chapter 6).

One of the reasons that the CBT approach obtained better results than the Group approach, may be that time was spent on examining, challenging and cognitively restructuring these illness representations, thus allowing patients to reassess their illness 'prototypes'.

The importance of illness representations was further underscored in the final study, chapter 7, which examined patient's beliefs about vitiligo. These results indicated that factors, such as education, which one would instinctively expect to be good predictors of patient's cognitive representations, were not in fact the best predictors, but rather cultural variables such as race and religion were more salient. As in the case of Biface and Walsh's (1979) study described earlier (see chapter 1), it appears that most patients, even those who have access to knowledge about their condition, have difficulty applying medical information to existing disease prototypes. Therefore, simply providing information to vitiligo patients about their condition may not be the key to helping them cope. Rather, eliciting and challenging already established illness representations may be more effective.

The way one conceptualises the 'meaning' of their condition will have implications for their beliefs regarding timeline, cause and even the

consequences of their illness. Several researchers have suggested that cognitive representations guide health behaviours (Leventhal et al., 1984; Meyer, et al., 1985; Leventhal et al, 1980; Bishop, 1990; Lau et al., 1989). The present results indicate that more than this, they guide the patient's view about themselves, the way they see the illness affecting their lives and the extent to which the psychosocial ramifications of their condition affect them. In a sense illness beliefs are a starting point from which patients can learn to accept and integrate their condition into the schema that they have of themselves as individuals living with vitiligo.

8.4 Theoretical Underpinnings

In chapter 1 it was suggested that the BPS model (Engel, 1977) and the Cognitive Representation of Illness Theory (Leventhal at al., 1984; Lau et al., 1989; Leventhal and Diefenbach, 1991) would serve as the main theoretical models upon which the studies could be underpinned. The discussion above suggests that both the theories were appropriate for use with this sample. The BPS model consistently helped to conceptualise the reciprocity between soma and psyche, and served as a useful explanatory model for interpreting results especially where onset or clinical course of the condition was a variable. The concept of illness representations was very effective in promoting an understanding of how beliefs were

implicated, not only in what patients felt caused their illness, but also in the way these beliefs maintained patient's views of themselves as 'vitiligo sufferers', and how such views aided or hindered adaptation to vitiligo.

A question that arises is how do the results of the studies inform these theories? In the case of the BPS model the results of the present study indicate that it is not merely that Bio-Psycho-Social variables interact in some abstract way to bring about varying states of health and illness, but rather, the results obtained have allowed us to hypothesise about, and propose, the psycho-physiological mechanisms through which this is possible. This is important since although the BPS model is relatively old in the field of health psychology, interpreting how biopsychosocial mechanisms work in vitiligo is a recent development in the field. Indeed, these results further inform the debate about the extent to which vitiligo has a psychosomatic component.

In the case of cognitive constructions of illness, the results of the studies enable us to postulate about how illness beliefs about vitiligo develop, not always through established medical knowledge, but to a greater extent through the context of one's culture. The results lend further support to the idea that people establish 'prototypes' about their condition, with regard to cure, consequences, control and course, and try and modify new information into existing cognitive structures. Interestingly, as in the case of Taylor (1983), who suggests that even those who are living with

diseases of unknown aetiology often hold strong views about the course and cause of their disease, similarly, although vitiligo is an episodic condition which can take an unpredictable course, patients still seemed to hold strong views about the 'timeline' of their condition. This suggests that patients have a need to possess *concrete* information about their illness, even if this type of information is unconfirmed medically. This need to 'know' about one's condition suggests that patients want to feel that they have some control of their illness, even though this control may have no foundation in existing medical knowledge.

Although much of the work on illness beliefs has centred around how to predict health behaviours, the studies described in the thesis were concerned with how these constructions informed patients' views about themselves as 'vitiligo sufferers'. The studies described in chapters 5 and 6 of the thesis, suggest that patient's concepts about themselves guided the way they interacted with others and the assumptions they made about the way that others related to them. This suggests that cognitive representations of illness are not only good for predicting future health behaviours, but also for making hypotheses about patients current level of psychological functioning. For example, if one can challenge, a person's belief that vitiligo is a form of punishment and something to feel guilty about, then they may be able to challenge their views about what other people think about them and in turn the way they interact with others.

The findings suggest that the conceptualisation of vitiligo within the theoretical framework of the biopsychosocial model and the complementary model of cognitive illness representations was useful, both in terms of how the results informed the theories and in terms of how the theories informed the results. In chapter 1 it was suggested that by underpinning our research with these models, that certain assumptions were being made, now we shall consider these assumptions in light of the current findings:

1. *People are not passive responders rather they are active problem solvers (Kelly, 1955), and thus their behaviour and mood is directed by their interpretations and perceptions of events.*

This premise seems to have been maintained by the current findings. There did not appear to be a simple cause and effect response to how the disfiguring nature of vitiligo affected patients. Rather, this seemed to vary according to how patients interpreted the reactions of others, the extent to which they attributed negative events in their life to their condition and how their beliefs, and the beliefs of those around them, about the cause, course and cure of their vitiligo were developed and maintained. The success of the CBT outcome study described in chapter 5, and in particular the way in which the decrease of negative cognitions appeared to have a positive

effect on patient functioning, suggests that patient behaviour and mood was to a great extent dependant upon interpretations of external events.

2. *To a large extent, the cognitive system that generates beliefs about vitiligo is not directly observable. What we do observe is the output of the cognitive-processing system through speech, behaviour and physiological changes.*

This assumption was also maintained. Patients beliefs about their condition most likely developed gradually, through their social and cultural environment (see chapter 7), although this process was not directly observable, the impact of the cognitive schemata that patients had developed were. The way that patients reported reacting to social situations (see chapters 5 & 6) gave us some insight into this cognitive processing system and the way that beliefs about vitiligo impacted upon personal and social encounters. Further the direct reporting of, often unfounded beliefs in chapter 7, and the fact that preliminary evidence was found to suggest that the onset and the progression of the illness were affected by psychological state (see chapters 4 & 5), underscore the idea that the observable manifestations of patient's beliefs/cognitive representations, came in the form of speech, behaviour and physiological change.

3. Cultural and social variables are significantly involved in the formulation of beliefs about illness and its consequences (Nelson, 1983).

Again, this idea was also supported by the current findings. Patient's illness beliefs did not appear to develop independent of their social or cultural surroundings. On the contrary, race and culture seemed to be the best predictors of illness beliefs (see chapter 7), suggesting that theories which do not account for the effects of a person's social environment, and more importantly a person's interpretation of this environment (see chapters 5 and 6) do not take into account all those variables which serve to shape and define the cognitive beliefs that patients hold about their vitiligo.

4. The relationship between vitiligo and psychological state is not linear, rather it is a reciprocal system with emergent properties.

This fourth and final assumption was also supported by the current findings, which suggest that there is evidence of a psychosomatic component in the onset and progression of vitiligo. Both the results of chapter 4 and chapter 5 underscore the fact that there is a reciprocal relationship between psychological state and the physical progression of the vitiligo. There has been an attempt to suggest the mechanisms through

which this systemic, relationship may be acting (see chapters 4 & 5), and underscore the reciprocity between physical and psychosocial systems in relation to vitiligo.

The results therefore have upheld the theoretical assumptions within which the present research was approached. Clearly however, there is a need for further investigation into the psychosocial effects of vitiligo, as well as the psychosomatic aspects of the condition. By furthering our understanding of the effects of this complex condition, we will hopefully be able to provide more efficacious and complete care to patients.

8.5 Coping with Disfigurement

Phrases like 'It's only a cosmetic disorder' or 'it has no debilitating effects', are often used by health professionals when speaking about vitiligo. Unfortunately these utterances capture neither the depth nor indeed the diversity of the vitiligo sufferer's experience. More importantly, they minimise the distress and feelings of self consciousness experienced by many patients. The disfiguring nature of vitiligo suggest that patients not only have to contend with the concept of themselves as 'ill', but also have to deal with an altered body image and in many cases objective

disfigurement. In the field of disfigurement research, one of the most commonly asked questions is what types of problems do people with an altered appearance face? Not surprisingly, given the social significance of one's appearance (Bull and Rumsey, 1988), many of the problems identified are related to social encounters and reactions from others. Literature has suggested that people whose appearance deviates from the norm have difficulties meeting new people (Porter et al., 1990) embarking on close personal relationships and, feeling positive about career goals and prospects (Beuf, 1990). The results of the studies described in the present thesis underscore this idea, with patients commonly reporting difficulties in 'exposing' their vitiligo to strangers, for fear of rejection and ridicule, and being anxious about what others think of their condition (see chapters 5 & 6).

Although there has been evidence to suggest that the general population do avoid contact with the facially disfigured (Rumsey and Bull, 1986; Rumsey et al., 1982) by such actions as averting their gaze, increasing their pace, or standing far away from the disfigured individual, it has also been suggested that these reactions are not necessarily to do with rejection. There is evidence to suggest that such reactions are a consequence of people's nervousness and uncertainty about how to behave in these situations (Rumsey and Bull, 1986). This notion proved particularly useful in devising and carrying out the CBT counselling protocol, used in chapter 5. An integral part of the counselling process was

helping patients to identify and challenge irrational or negative thoughts. Although it was not always 'irrational' to think that people where being stared at or that their condition was being discussed, it was possible to assign reasons (that had to do with the other person in the social encounter as opposed to the disfigured individual) as to why this was happening. Patients were able to externalise these reactions by conceptualising them as people displaying curiosity or unease as opposed to feeling that they were simply unsightly those around them. The challenging of negative thoughts was identified by patients as one of the most useful coping tools that they had acquired through counselling.

In an excellent discussion by Moss (1997) on variations in coping style of people with various disfigurements, the author suggest that coping is not a simple task but rather it is a dynamic process which relies on a variety of strategies used at different times. Strategies ranging from confronting risk and seeking social support to venting emotions and the use of religion have been cited as useful coping mechanisms (Lazarus, 1993). However, in general terms, the author suggests that the concept of coping can be divided into the broad categories of: emotion-focused-coping and problem-focused-coping. The former deals with the way people attend to threat. That is, trying to change the way they think about a threat, so as to neutralise it or make it less threatening. An example of this was described above where patients were taught to challenge their perceptions of social situations where they felt that their appearance was being scrutinised. The

latter involves actually changing the threat itself, or doing something about it. This was also taken into account when devising the CBT counselling protocol. Patients were taught practical tools for how to deal with staring, rude comments and how to confront other difficult social situations. Reports from participants in the studies suggest that they used both types of coping mechanisms, in some cases simultaneously and in others fluctuating between the two depending on the situation. Moss (1997) suggests that in cases where a person can exert control over the threat then problem focused coping is effective, whereas in cases where the threat is not directly controllable then emotion-focused coping is more useful.

Of course, in most cases both strategies are used, both during and after a stressful event and the extent to which they prove to be useful will depend on the context in which they are used. The social support (Kleber and Brom, 1992), social skills (Rumsey et al., 1986), optimism (Apsinwall and Taylor, 1992) and attributional style (Crocker, et al., 1991) that a person possesses will all affect the way in which, and how effectively, they will cope with particular stressors. As Moss (1997) notes however, there is no simple model that accounts for why some people adjust well to the challenges of disfigurement while others do not. One thing that emerges from this thesis however, is that equipping people with efficacious problem-focused and emotion-focused coping tools can positively affect their ability

to deal with their condition, which in turn affects psychological variables such as self esteem and body image.

Different researchers in the area of skin disease and disfigurement have suggested that living with the challenges of an appearance which deviates from the norm can result in a variety of psychological problems including low self esteem, social anxiety, low self concept and depression (Kent et al., 1995; Porter et al., 1990; Ginsburg and Link, 1989; Robinson, 1997). The results of the present thesis uphold this, suggesting that vitiligo sufferers have significantly lower self esteem, body image and quality of life than the general population. However others have found that people with disfigurements such as those with burns (Blakeney, et al., 1988) port wine stains (Kalick, et al., 1981) and cranio-facial deformities, cope well with their appearance and in some cases do not differ at all in terms of psychological adjustment to their non-disfigured counterparts (Blakeney, et al., 1988). Recent research has sought to examine what it is that will allow one person to adapt to, and cope well with, their condition while another to become a social recluse.

An initial hypothesis might be that the severity of the disfigurement will be a good predictor of adjustment. That is, to assume that patients who have more obvious or severe deformities are affected to a greater extent by their condition than those whose disfigurements are mild. Some researchers have in fact suggested that the visibility of the condition may be a factor in

adjustment (i.e. Grifiths, 1991; Hughes et al., 1983). However this hypothesis is not supported by either the findings of the present thesis or by various studies in the field more generally (i.e. Baker, 1992; Malt and Ugland, 1989; White, 1982). In the results of the present thesis one would have expected vitiligo patients who were darker skinned to be more negatively affected by their condition than those with lighter skins, since the lesions are much more salient on highly pigmented skins. However this was not the case, in the study described in Chapter 7, Afro-Caribbean/European respondents were not found to be significantly more depressed than Caucasian respondents. The fact that Indian members of the sample were found to be significantly more negative about the consequences of their condition than either Black or White respondents suggests that a more culturally bound explanation for this negative self image is more likely (see discussion Chapter 7).

Another hypothesis regarding adjustment might be that women are more affected by their condition than are men. This belief stems from research which suggests that women spend more money on improving their physical attractiveness (Kleinman, 1988) and experience more psychological illness thought to be related to body image such as anorexia and bulimia than men (Cash, 1990). Furthermore, Rumsey (1997) has noted that gender differences clearly exist in terms of the societal norms women are expected to conform to. A woman's self worth may be linked to her perception of how she looks and how others perceive her, whereas a man's self-worth

may be dependant more so on factors of physical fitness and effectiveness (Lerner, et al., 1973). It might therefore be reasonable to hypothesise that women will be more distressed and have more adjustment problems to disfigurement than their male counterparts. However, once again this was not the case in the present research. Women were not found to have more negative concepts of their vitiligo in terms of control, cause, consequence or timeline. Unfortunately, the effects of sex could not be examined in the other studies due to the small sample size. However, anecdotally, it might be important to note that no significant difference in terms of the psychological effect of disfigurement was noted in either of the outcome studies (chapters 5 and 6) between the two sexes. These results are in parallel with those of Brown and his colleagues (1988) who found no gender differences in the psychological adjustment of male and female burn victims. However, the authors noted that the methods employed for adjustment varied between the two sexes. The main predictors for male adjustment were low functional disability, low use of avoidance coping and being involved in recreational activities and for females problem solving, low functional disability and family support. It appears, therefore, that differences may lie not in psychological adjustment to disfigurement but rather in the coping methods used to aid adjustment (Robinson, 1997).

Another idea that has received attention both in the disfigurement and in the handicap literature is the notion that the longer someone lives with a condition, the easier it will become to cope with it (Malt, 1980; Patterson,

1993). The present studies lend some support to this idea. Older respondents and those who had lived with vitiligo over long periods, displayed more positive adjustment in terms of the consequences of their illness, than did the younger cohort (see chapter 7). It should be noted, however, that due to the fact that the study employed a cross-sectional as opposed to a longitudinal design, that it is not possible to say whether the 'well adjusted older sample' had become better adjusted over time or whether they had always been able to adjust well to illness related issues. This has been one of the main methodological errors with most research which has tried to establish the effect of healing power of time on disfigurement (i.e. Tucker, 1987).

Much of the research in the field of disfigurement has focused on identifying the problems that exist for disfigured populations (i.e. Patterson et al., 1993; Macgergor, 1989; Macgregor, 1990) and more recently on the factors which affect adjustment to disfigurement (Baker, 1992; Williams and Griffiths, 1991; Patterson et al., 1993). However, few attempts, have been made to establish practical ways that professionals can help people with disfigurements cope with their condition.

Having identified the problems that the disfigured population may face and the way the factors that can affect adjustment we need to examine how mental health professionals can facilitate coping with the challenges of disfigurement.

A large part of the present thesis investigated the outcome of psychological therapy on coping with an altered appearance. An attempt was made to undertake controlled studies to examine the effectiveness of psychological therapy. What emerges from the studies is the idea that people with disfigurement require more than supportive counselling in order to cope with their condition. This is in agreement with the results of other studies in the field which have examined the efficacy of counselling with disfigurement and physical handicap (Cash and Pruzinsky, 1990; Grant and Cash, 1993; Rosen et al., 1989). Robinson et al, (1996), have reported success with structured groups run for disfigured individuals, where social skills training was an integral part of the group process. Cash (1990) has reported success with the use of cognitive based therapies for people with body image disturbance. More recently a group of psychologists who specialise in disfigurement based referrals called 'Outlook', have cited very promising results with the CBT based therapies that they offer. Unfortunately, the importance of psychological care in the rehabilitation process is often minimised or overlooked by many of those working in the field. Although some health care settings offer patient-led self-help groups or befriending schemes where new patients are given the chance to meet old patients, rarely do they have the opportunity to engage in therapy with trained professionals. One of the few studies which examined what type of support patients felt they needed following discharge (Wallace, 1988), found that 88% reported that they would have

liked professional support. This suggests that more effort needs to be placed on examining which approaches to psychological treatment are most efficacious and which of these best meet patient needs.

What is evident, both from the studies described in the thesis and previous research in this area, is that people think about and assess situations and that these assessments dictate their reactions to the situations. Further these beliefs may affect physiological functioning (Levy and Wise, 1987; Antoni, 1987, Peterson, 1986). As described in chapter 1 this can set up a reciprocal system whereby beliefs and cognitive representations affect the physical progression of vitiligo and vice versa. It is therefore imperative that psychologists, counsellors, dermatologists and other health care professionals take into account these interpretations and acknowledge the individual differences that exist with regard to how people 'cope' with disfigurement.

8.6 Identifying the Importance of Collaborative Relationships Between Psychologists and Dermatologists

The importance of active working relationships, both with regard to clinical and academic work, between dermatologists and psychologists has been underscored in the studies described. There appears to be a need to provide patients with the opportunity to explore and express their feelings

about their condition, following a diagnosis or indeed during the treatment. Similarly, there is also a need for psychologists to be able to identify psychocutaneous illnesses and refer to dermatologists where a collaborative approach to treatment might be useful. With regard to research it is vital that professionals from both fields establish good working relationships, where knowledge can be shared and the understanding of the links between psychology and dermatology can be advanced. Some of the ways that these links might be strengthened include:

1. Establishing psychology services within dermatology clinics. This would serve to de-stigmatise the role of counselling and psychology, and normalise the idea that patients may need to discuss the psychological implications as well as the physical manifestations of their condition. Further, it might facilitate communication between psychologists and dermatologists about client needs and their treatment.

2. Finding more efficient ways to share information between psychologists and dermatologists at a theoretical level. This might include setting up professional psycho-dermatology groups where research is discussed and presented, formally and informally throughout the year. Perhaps from this, the development of a professional journal in the field might materialise. At present attempting any sort of literature search in the field requires reviewing a vast amount of journals in both fields most of which have an

'imbalanced bias' towards one of the two disciplines. Setting up collaborative working relationships might serve to reduce some of these imbalances and provide a forum where ideas from the entire field can be drawn together.

3. Professional clinical seminars led by psychologists could be established where information about patient care and counselling can be disseminated to dermatologists and nurses working in the field. These could take the form of workshops where dermatologists and nurses could learn basic counselling techniques that would help them to acknowledge the psychological impact of their patient's condition and address their patients needs more effectively.

4. Having seminars or discussion groups led by dermatologists where psychologists are informed of the physical nature of various conditions, the treatment for these and what type of medications tend to be prescribed. This would allow psychologists to take into account the effects of treatment, and outcome on their patient's psychological status and allow them to empathise more effectively with their patients and to formulate more informed hypothesis about their patients based on this information.

Whether or not it is realistic to assume that those responsible for patient care will acknowledge the importance of collaborative relationships between dermatologists and psychologists remains to be seen. However, as psychologists working in the field of psycho-dermatology and more generally in the field of disfigurement, it is imperative that we keep underscoring the importance of the psychological dimension of illness and highlighting the need to translate research such as that described herein, into concrete clinical practice.

Many questions have been generated as well as answered by the studies contained in this thesis. However, a theme that has been repeatedly highlighted, is that the effects of vitiligo are more than skin deep. In a world where so much importance is placed on physical appearance and characteristics, it is increasingly likely that people will be adversely affected by the social and psychological consequences of any stigmatising and disfiguring condition. As health professionals, we have a duty to understand the illness experience of our patients, and seek to explore new methods and treatments for giving them the best care possible.

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APPENDIX

Appendix 1

SCHEDULE OF RECENT EXPERIENCE (SRE)

RD NO. ___ (1) DATE _____ (4) (5)

OUP NO. ___ (2) ___ (3) ID NO. ___ (6) ___ (7) ___ (8) ___ (9) ___ (10)

AME_____ADDRESS_____

E____ (11, 12) SEX: Male____Female____ (13) _____

ARITAL STATUS: Married ____Divorced ____Separated ____Widowed ____Never married ____ (14)

DUCATION: Grade school____High school ____Trade school ____College ____Advanced degree ____ (15)

STRUCTIONS:

reach life event item listed below please do the following:

Think back on the event and decide if it happened during the last 12 months. If the event did happen, indicate the *number of times* it happened by placing a number in the column labeled 0–12 months ago.

	0–12 months ago
A lot more or a lot less trouble with the boss.	____ (16)
A major change in sleeping habits (sleeping a lot more or a lot less, or change in part of day when asleep).	____ (17)
A major change in eating habits (a lot more or a lot less food intake, or very different meal hours or surroundings).	____ (18)
A revision of personal habits (dress, manners, associations, etc.).	____ (19)
A major change in your usual type and/or amount of recreation.	____ (20)
A major change in your social activities (e.g., clubs, dancing, movies, visiting, etc.).	____ (21)
A major change in church activities (e.g., a lot more or a lot less than usual).	____ (22)
A major change in number of family-get-togethers (e.g., a lot more or a lot less than usual).	____ (23)
A major change in financial state (e.g., a lot worse off or a lot better off than usual).	____ (24)
In-law troubles.	____ (25)
A major change in the number of arguments with spouse (e.g., either a lot more or a lot less than usual regarding child-rearing, personal habits, etc.).	____ (26)
Sexual difficulties.	____ (27)
Major personal injury or illness.	____ (28)
Death of a close family member (other than spouse).	____ (29)
Death of spouse.	____ (30)
Death of a close friend.	____ (31)
Gaining a new family member (e.g., through birth, adoption, oldster moving in, etc.).	____ (32)

	0–12 months ago
8. Major change in the health or behavior of a family member.	11
9. Change in residence.	14
0. Detention in jail or other institution.	18
1. Minor violations of the law (e.g., traffic tickets, jaywalking, disturbing the peace, etc.).	20
2. Major business readjustment (e.g., merger, reorganization, bankruptcy, etc.).	37
3. Marriage.	36
4. Divorce.	39
5. Marital separation from spouse.	40
6. Outstanding personal achievement.	41
7. Son or daughter leaving home (e.g., marriage, attending college, etc.).	42
8. Retirement from work.	43
9. Major change in working hours or conditions.	44
0. Major change in responsibilities at work (e.g., promotion, demotion, lateral transfer).	45
1. Being fired from work.	46
2. Major change in living conditions (e.g., building a new home, remodeling, deterioration of home or neighborhood).	47
3. Wife beginning or ceasing work outside the home.	48
4. Taking out a mortgage or loan for a major purchase (e.g., purchasing a home, business, etc.).	49
5. Taking out a mortgage or loan for a lesser purchase (e.g., purchasing a car, TV, freezer, etc.).	50
6. Foreclosure on a mortgage or loan.	51
7. Vacation.	52
8. Changing to a new school.	53
9. Changing to a different line of work.	54
0. Beginning or ceasing formal schooling.	55
1. Marital reconciliation with mate.	56
2. Pregnancy.	57

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ISBN No. 295-77007-4
Distributed by the University of Washington Press,
Box 85569, Seattle, Washington 98105

Appendix 2

DERMATOLOGY LIFE QUALITY INDEX

DLQI

Hospital No:
Name:
Address:

Date:

Diagnosis:

Score: ☐

The aim of this questionnaire is to measure how much your skin problem has affected your life OVER THE LAST WEEK. Please tick ✓ one box for each question.

1. Over the last week, how itchy, sore, painful or stinging has your skin been?

Very much ☐
A lot ☐
A little ☐
Not at all ☐

2. Over the last week, how embarrassed or self conscious have you been because of your skin?

Very much ☐
A lot ☐
A little ☐
Not at all ☐

3. Over the last week, how much has your skin interfered with you going shopping or looking after your home or garden?

Very much ☐
A lot ☐
A little ☐
Not at all ☐
Not relevant ☐

4. Over the last week, how much has your skin influenced the clothes you wear?

Very much ☐
A lot ☐
A little ☐
Not at all ☐
Not relevant ☐

5. Over the last week, how much has your skin affected any social or leisure activities?

Very much ☐
A lot ☐
A little ☐
Not at all ☐
Not relevant ☐

6. Over the last week, how much has your skin made it difficult for you to do any sport?

Very much ☐
A lot ☐
A little ☐
Not at all ☐
Not relevant ☐

7. Over the last week, has your skin prevented you from working or studying?

Yes ☐
No ☐
Not relevant ☐

If "No", over the last week how much has your skin been a problem at work or studying?

A lot ☐
A little ☐
Not at all ☐

8. Over the last week, how much has your skin created problems with your partner or any of your close friends or relatives?

Very much ☐
A lot ☐
A little ☐
Not at all ☐
Not relevant ☐

9. Over the last week, how much has your skin caused any sexual difficulties?

Very much ☐
A lot ☐
A little ☐
Not at all ☐
Not relevant ☐

10. Over the last week, how much of a problem has the treatment for your skin been, for example by making your home messy, or by taking up time?

Very much ☐
A lot ☐
A little ☐
Not at all ☐
Not relevant ☐

Please check you have answered EVERY question. Thank you.

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Appendix 3

ROSENBERG SELF-ESTEEM SCALE

Name:.....

Date:..... Record Number:.....

Here is a list of statements dealing with your general feelings about yourself. If you agree with the statement, circle A. If you **strongly agree**, circle SA. If you **disagree**, circle D. If you **strongly disagree**, circle SD. Thank you.

	1. Strongly agree	2 Agree	3 Disagree	4 Strongly disagree
1. On the whole, I am satisfied with myself.	SA	A	D	SD
2. At times I think I am no good at all.	SA	A	D	SD
3. I feel that I have a number of good qualities.	SA	A	D	SD
4. I am able to do things as well as most other people.	SA	A	D	SD
5. I feel I do not have much to be proud of.	SA	A	D	SD
6. I certainly feel useless at times.	SA	A	D	SD
7. I feel that I'm a person of worth, at least on an equal plane with others.	SA	A	D	SD
8. I wish I could have more respect for myself.	SA	A	D	SD
9. All in all, I am inclined to feel that I am a failure.	SA	A	D	SD
10. I take a positive attitude toward myself.	SA	A	D	SD

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Appendix 4

THE SIBID

At various times and in various situations, people may experience negative feelings about their own physical appearance. Such feelings include feelings of unattractiveness, physical self-consciousness, or dissatisfaction with one or more aspects of one's appearance. This questionnaire lists a number of situations and asks how often you have feelings about your appearance in each of these situations.

Think about times when you have been in the situation and indicate how often you have had any negative feelings about your physical appearance in that situation. Use the 0 to 4 scale provided to indicate HOW OFTEN you have negative feelings about your physical appearance in each of the situations:

0	1	2	3	4
Never	Sometimes	Moderately Often	Often	Always or Almost Always

There may be situations on the list that you have not been in or that you avoid. For these situations; simply indicate how often you believe that you would experience negative feelings about your appearance if you were in the situation.

Please answer accurately and honestly. There are no right or wrong answers, and your responses are anonymous and confidential.

HOW OFTEN?

_____ 1. At social gatherings where I know few people

_____ 2. When I look at myself in the mirror

_____ 3. When I am the focus of social attention

_____ 4. When people see me before I've "fixed up"

_____ 5. When I am with attractive persons of my sex

_____ 6. When I am with attractive persons of the other sex

_____ 7. When someone looks at parts of my appearance that I dislike

_____ 8. When I look at my nude body in the mirror

_____ 9. When I am trying on new clothes at the store

HOW OFTEN DO YOU HAVE NEGATIVE FEELINGS ABOUT YOUR APPEARANCE?
0=Never, 1=Sometimes, 2=Moderately Often, 3=Often, 4=(Almost) Always

---

HOW OFTEN?

_____ 10. When I am exercising

_____ 11. After I have eaten a full meal

_____ 12. When people can see me from certain angles

_____ 13. When I am wearing certain "revealing" clothes

_____ 14. When I see attractive people on television or in magazines

_____ 15. When someone compliments me on my appearance

_____ 16. If I'm dressed differently than others at a social event

_____ 17. When I get on the scale to weigh

_____ 18. When I think someone has ignored or rejected me

_____ 19. When anticipating or having sexual relations

_____ 20. If my friend or partner doesn't notice when I'm "fixed up"

_____ 21. When I'm already in a bad mood about something else

_____ 22. When the topic of conversation pertains to appearance

_____ 23. When I think about how I looked earlier in my life

_____ 24. When I haven't exercised as much as usual

_____ 25. When someone comments unfavorably on my appearance

_____ 26. When my clothes don't fit just right

_____ 27. When my partner sees me undressed

_____ 28. When I see myself in a photograph or videotape

_____ 29. When I think I have gained some weight

_____ 30. When I think I have lost some weight

_____ 31. When somebody else's appearance gets complimented and nothing is said about my appearance

HOW OFTEN DO YOU HAVE NEGATIVE FEELINGS ABOUT YOUR APPEARANCE?
0=Never, 1=Sometimes, 2=Moderately Often, 3=Often, 4=(Almost) Always

---

HOW OFTEN?

_____ 32. When I hear someone criticize another person's looks

_____ 33. After I get a new haircut or hairstyle

_____ 34. If my partner touches me in body areas that I dislike

_____ 35. When I think about what I wish I looked like

_____ 36. When I am not wearing any make-up

_____ 37. When I recall any kidding or unkind things people have said about my appearance

_____ 38. When I think about how I may look in the future

_____ 39. When I have my photograph taken

_____ 40. If my hair isn't fixed just right

_____ 41. If my partner doesn't show sexual interest

_____ 42. When I am with people who are talking about weight or dieting

_____ 43. When I am with a certain person (Specify whom: _____)

_____ 44. At particular times of the day or evening (Specify when: _____)

_____ 45. During particular times of the month (Specify when: _____)

_____ 46. During particular seasons of the year (Specify when: _____)

_____ 47. During certain recreational activities (Specify which: _____)

_____ 48. When I eat certain foods (Specify which: _____)

_____ 49. Any other situation? _____

_____ 50. Any other situation? _____

Appendix 5

Appearance Thoughts Questionnaire (BIATQ/Cash)

Listed below are a variety of thoughts about personal appearance that sometimes pop into people's heads. Please read each thought and indicate how frequently, if at all, the thought occurred to you over the last week.
Please read each item carefully. Using the following scale as a guide, for each item please backen the circle on the answer sheet that best describes your thoughts during the past week.

1	2	3	4	5
Never	Sometimes	Moderately Often	Often	Very Often

1. I am so self-conscious about how I look.
2. I am helpless to change my appearance.
3. My life is lousy because of how I look.
4. My looks make me a nobody.
5. I don't look good enough to be here.
6. Why can't I ever look good?
7. It's just not fair that I look like I do.
8. With my looks, nobody is ever going to love me.
9. I wish I were better looking.
10. Other people think I'm good looking.
11. I can tell that other people think I'm unattractive.
12. I must lose weight.
13. They think I look fat.
14. My appearance helps me to be more confident.
15. They're laughing about my looks.
16. Maybe I could look like him/her.
17. I'm not attractive.
18. I am proud of my body.
19. He/she won't sit by me because I'm not good looking.

1	2	3	4	5
Never	Sometimes	Moderately Often	Often	Very Often

20. I wish I looked like someone else.

21. My body has good proportions.

22. Others won't like me because of how I look.

23. My looks seem to help me socially.

24. I'll never be attractive.

25. I hate my body.

26. I like the way I look.

27. Something about my looks has to change.

28. I still think I'm attractive even when I'm with people more attractive than me.

29. How I look ruins everything for me.

30. I'm at least as attractive as most people.

31. I can never look the way I want to.

32. I'm so disappointed in my appearance.

33. Everybody looks better than I do.

34. I feel unattractive, so there must be something wrong with my looks.

35. I don't mind people looking at me.

36. I'm comfortable with my appearance.

37. I wish I didn't care about how I look.

38. Other people notice "right off the bat" what's wrong with my body.

39. People are thinking I'm unattractive.

40. I look healthy.

41. I don't like with the way I look in my bathing suit.

1	2	3	4	5
Never	Sometimes	Moderately Often	Often	Very Often

42. I'm so ugly.

43. They look better than me.

44. I especially think I'm unattractive when I'm with attractive people.

45. I can't wear stylish clothes.

46. My body needs more definition.

47. These clothes look good on me.

48. My clothes just don't fit right.

49. I wish others wouldn't look at me.

50. My body isn't perfect, but I think it's attractive.

51. I don't need to change the way I look.

52. I can't stand my appearance anymore.

Appendix 6

I.P.Q.
YOUR VIEWS ABOUT YOUR ILLNESS

Please tick how often you experience the following ***symptoms as part of your illness.***

SYMPTOM	ALL THE TIME	FREQUENTLY	OCCASIONALLY	NEVER
Pain				
Nausea				
Breathlessness				
Weight Loss				
Fatigue				
Stiff Joints				
Sore Eyes				
Headaches				
Upset Stomach				
Sleep Difficulties				
Dizziness				
Loss of Strength				

We are interested in your own personal views of how you now see your illness. Please indicate how much you agree or disagree with the following statements about your illness.

	VIEWS ABOUT YOUR ILLNESS	STRONGLY AGREE	AGREE	NEITHER AGREE NOR DISAGREE	DISAGREE	STRONGLY DISAGREE
IP1	A germ or virus caused my illness					
IP2	Diet played a major role in causing my illness					
IP3	Pollution of the environment caused my illness					
IP4	My illness is hereditary - it runs in my family					
IP5	It was just by chance that I became ill					
IP6	Stress was a major factor in causing my illness					
IP7	My illness is largely due to my own behaviour					
IP8	Other people played a large role in causing my illness					
IP9	My illness was caused by poor medical care in the past					
IP10	My state of mind played a major part in causing my illness*					

I.P.Q

YOUR VIEWS ABOUT YOUR ILLNESS (Continued)

	VIEWS ABOUT YOUR ILLNESS	STRONGLY AGREE	AGREE	NEITHER AGREE NOR DISAGREE	DISAGREE	STRONGLY DISAGREE
IP11	My illness will last a short time					
IP12	My illness is likely to be permanent rather than temporary					
IP13	My illness will last for a long time					
IP14	My illness is a serious condition					
IP15	My illness has had major consequences on my life					
IP16	My illness has become easier to live with					
IP17	My illness has not had much effect on my life					
IP18	My illness has strongly affected the way others see me					
IP19	My illness has serious economic and financial consequences					
IP20	My illness has strongly affected the way I see myself as a person					
IP21	My illness will improve in time					
IP22	There is a lot which I can do to control my symptoms					
IP23	There is very little that can be done to improve my illness					
IP24	My treatment will be effective in curing my illness					
IP25	Recovery from my illness is largely dependent on chance or fate					
IP26	What I do can determine whether my illness gets better or worse					