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# 1

# Introduction

Carl Walker

> '…You become introverted, avoid contact, become depressed, obsessive in looking at other people, hoping to see someone else who is affected. You undergo a personality change very slowly and bit by bit, a strong person is reduced to isolation. You become angry, sad and desperate. After time, it becomes an operation just to go out of your front door …'. 27-year-old female discussing her 15-year vitiligo history.
>
> *APGS Call for Evidence* (2003)

The skin has long been recognised as the 'organ of expression' (Sack, 1928) and serves as the boundary between ourselves and the outside world, a 'first point of contact' when strangers meet us. It is also the largest organ of the body. The ways in which the skin can react to many different stimuli, both physiological (i.e. a rash caused by an external noxious substance) and psychological (an individual may blush when feeling embarrassed) highlight the complexity of the relationship between the skin, and external and internal factors. Dermatological disorders have an immediate impact on tactile communication, sexual contact and bodily interaction in particular and fear, anxiety and shame as well as sexual pleasure and excitement can be indicated visibly by growing pale, blushing and hair rising (Van Moffaert, 1992).

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 may have an impact on psychosocial functioning, relatively little attention has been paid to the psychosocial problems experienced by skin disease sufferers. Skin disease patients have direct access to their skin lesions and so can have a very direct impact on the progress of their condition and this is not the case with many other diseases. Since most skin conditions are accompanied by pain and discomfort, it can be difficult to assess the differential and combined effects of the physiological and psychosocial aspects of the condition on an individual's quality of life and self-esteem. However, psychological factors have long been known to be associated with dermatological conditions (Wilson, 1863; Engles, 1982) but only recently has there has been an accumulation of literature on the link between adult dermatology and psychosocial problems (e.g. Al'Abadie, 1994; Papadopoulos & Bor, 1999). Some of the issues which have been explored in recent research have tended to focus on morbidity in the areas of depression, anxiety, self-esteem, body image, quality of life and relationship/sexual issues (Papadopoulos & Walker, 2003). This focus on the potential psychosocial conflict caused by dermatological conditions indicates the range of issues pertinent to the holistic experience of skin disease.

## Skin disease and psychology: a multitude of links

Psychological factors have been linked to dermatological illness in several and varied ways. Some authors have linked the aetiology of cutaneous illness to various psychological morbidities, ranging from Freud's conception of hysterical conversion mechanisms (Strachey, 2001) to Sheppard et al.'s (1986) notion of specific neurophysiological disturbances. Psychocutaneous phenomena have been classified in the past using personality-specific conflict and cutaneous symptoms (Obermeyer, 1985) and it was not until 1983 that Koblenzer posited a classification system comprising three specific, main categories of psychocutaneous illness:

- Conditions that are exclusively psychological in origin.
- Conditions in which strong psychogenic factors are implicated (i.e. urticaria).
- Conditions which are dependent on genetic and environmental factors but in which the course of the disease is substantially influenced by stress (vitiligo, eczema).

In 1992, Koblenzer modified this taxonomy to account for developments in the understanding of the influence of immune factors and the system became:

- Cutaneous manifestations of psychiatric disease.
- The effect of psychosocial stress on latent or a manifestation of cutaneous disease.
- The somatopsychic effect.

It has been estimated that between 40% and 80% of patients attending a dermatological outpatient clinic have experienced significant psychological or psychiatric problems, and Cotterill (1989) posited that these patients arose from five convenient and more detailed classifications:

- Individuals who experience psychosocial morbidity such as depression as a result of their skin disease. Visibility is considered to play a particular role in this group and it is not uncommon for these feelings to develop towards suicidal ideation.
- A more contentious group are those patients in whom it is believed that their skin disease has developed as a result of exposure to excessive stress or strain. Whilst this is a difficult area to quantify, there are considerable data (Van Moffaert, 1992;

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Liu et al., 1996; Papadopoulos et al., 1998) to indicate that stress plays a profound role in the precipitation of a number of skin diseases including vitiligo, eczema, psoriasis, acne and urticaria.

- A third group of patients are those which present with factitious disorders such as dermatitis artefacta, trichotillomania, and oedema of the legs or arms.
- Some patients suffer dermatological delusional disease in which the commonest psychiatric assessment reveals depression. Patients present with some physical complaint relating to the skin or hair and delusions of parasitosis, the most common of these conditions is actually very rare. These patients are generally regarded to have monosymptomatic hypochondriacal psychosis.
- Finally, there is a group of patients who may develop dermatological disorders as a result of pharmaceutical therapy and the induction of acne and psoriasis in susceptible individuals who imbibe lithium is one example.

Skin diseases are more often than not accompanied by changes in the person's physical appearance and these changes are often obvious to others. This generates two major consequences. Firstly, the visibility of the condition may well be noticeable to others and draw people's attention. This can remove the feeling of personal control from the sufferer, as they no longer control when and how others know about their disease. It can often feel like their condition becomes 'public property' whereas many non-visible, internal diseases allow the sufferer to control who knows about their condition and when.

Secondly, skin disease has often been associated with myths surrounding lack of hygiene and contagion (Kleinman, 1988). This can influence others to act negatively towards the sufferer and hence often generate feelings of profound stigma. The fact that skin disease can often be progressive and episodic means that sufferers can sometimes feel that they constantly have to adapt to the changes in their physical appearance. It is often found that patients begin to feel handicapped and avoid social situations where their skin disease can be viewed by others and they can tend to have a poorer body image and lower self-esteem than the general population (Papadopoulos et al., 1999).

The episodic nature of many skin conditions also affects the way that patients conceptualise the cause of their condition. Uncertain aetiology combined with oscillating severity can cause sufferers to generate their own reasoning for their periods of exacerbation (Papadopoulos & Walker, 2003). This can lead to the avoidance of behaviours, places and events that may have no actual significance as regards symptom severity and this avoidance can be detrimental to the individual's quality of life. Negative reactions from others and a fear of such reactions can be one challenge of the skin disease experience that has to be met. The 'just world hypothesis', the idea that a person must somehow deserve their disfigurement as an

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appropriate punishment for previous transgressions (Goffman, 1968) together with the fear of contagion and uncertainty as to how to approach an individual with a visible difference can combine to make the experience of having a skin disease deeply challenging. Often, when people develop any severe or chronic ailment, they will question why they have developed the condition or what they have done to deserve this disease. This kind of thought process often implies a sense of punishment for some kind of wrongdoing and can carry feelings of guilt. Indeed, very often people with skin diseases link skin lesions to sexual causation and contagion themselves. Furthermore, when there is an insult to one's 'normal' sense of self which falls short of the 'ideal self', feelings of shame often ensue. Thoughts and concerns about the skin lesion are often displaced onto the self as a whole, as though patients form the syllogism: skin lesions are ugly, I have skin lesions, therefore I am ugly (Papadopoulos & Walker, 2003).

Updike (1990) has written eloquently about the enacted stigma of the psoriasis sufferer. He believed that the tendency for non-sufferers to turn away from people with skin disease or to feel disconcerted stems from a fleeting identification with the person who is afflicted. The affected person symbolises our own vulnerability and imperfection, our defensiveness and lack of autonomy. Updike speculates that we turn away from those who remind us of our own inherent humanity and vulnerability.

## Skin disease and body image

To understand the social and psychological experience of living with a skin disease, it is essential for health professionals to understand patients' cognitions and the ways in which they represent their illness and their sense of self (Weinman et al., 2000).

Body image can be hypothesised as the 'inside view' that pertains to our own highly personalised experiences of our looks. For many people in society, body experiences are fraught with discontent, unhappiness and self-conscious preoccupation, and body image problems are difficulties in their own right, contributing as they do to a large range of psychological disturbances (Papadopoulos & Walker, 2003).

Early in the 20th century, body image concepts and studies had a tendency to focus on neurologically impaired patients. Although this brought the area of body image into the domain of scientific study, little attention was paid to the psychological aspects of body experience. More recently this has changed and in the past 20 years, much of the research on body image has emanated from a burgeoning interest in clinical eating disorders. Indeed much has been gained from this marriage of body image and eating disorders research but there have also been detrimental consequences (Cash & Brown, 1987). Body image has tended to become synonymous with either distorted body width estimates or a general emphasis on

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weight. As such, other aspects of body image such as skin disease have tended to be sidelined.

Cash and Pruzinsky (1990) delineated several integrative themes from the body image literature and concluded that body images were multifaceted and referred to perceptions, feelings and thoughts about the body. Body image feelings are intertwined with feelings about the self and body images have a strong social component. That is, interpersonal meaning and cultural socialisation define the social meaning of physical aesthetics and the personal meanings of an individual's physical characteristics. Furthermore, Cash and Pruzinsky showed that body images were not static but could operate on both trait and state levels, and so could be free to interact with the episodic nature of a range of factors including external, social events and the presence of a disfiguring condition such as skin disease. This is particularly relevant to skin disease patients since their conceptualisation of their body image may vary with the episodic nature and visibility of their disease (Thompson et al., 2002).

It has been reported that there are moderate associations between body dissatisfaction and poor psychological adjustment for men and women across the lifespan (Cash, 1985) and research has revealed that evaluative body image accounts for around a quarter to a third of variance in global self-esteem (Cash & Pruzinsky, 1990). As such, body satisfaction can have a considerable influence on psychosocial health. The literature has also shown a relationship between body satisfaction and depression (Noles et al., 1985), social confidence and social evaluation anxiety (Cash, 1993).

## Self-schema(s) and body image

The core of body image dissatisfaction is a discrepancy between a person's perceived body and their ideal body. A failure to match these leads to self-criticism, guilt and low self-worth. Self-schema is a mental representation of those elements that make an individual different from other people. Myers and Biocca (1992) view a person's body image as one aspect of the mental representation that constitutes the self. As with other aspects of the self, the body image is a mental construction, not an objective evaluation. The authors believe that a number of reference points exist that a person will draw upon when constructing their mental model of body image. These include the 'socially represented ideal body' (ideals represented in the media, and drawn from peers and family), the objective body and the 'internalised ideal body' (a compromise between the objective body and the socially represented ideal). They argue that the body image is elastic in that its reference points frequently change since it depends on mood and the presence of social cues.

Cash and Pruzinsky (1990) believe that specific contextual events serve to activate schema-driven processing of information about, and self-appraisals of, one's body

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appearance. Implicit or internal dialogues such as automatic thoughts, interpretations and conclusions are termed ‘private body talk’. In the case of individuals with skin disease who have a negative body image, this private talk can reflect habitual and faulty patterns of reasoning and the commission of specific cognitive errors. Among the defensive actions which may arise from these cognition’s are avoidant and concealment behaviours, compulsive correcting rituals and social reassurance seeking.

## The psychological impact of skin disease

It has been suggested that people whose appearance deviates from the norm have a more acute sense of awareness of their own bodies and the associated pressure to comply with social standards. This pressure has personal and social implications such as affecting relationships and hobbies (Porter et al., 1987), quality of life and expectations (Lanigan & Cotterill, 1989), and career aspirations (Goldberg et al., 1975).

Research into the manifestations of psychocutaneous disorders has led to an increasing awareness of the psychosocial effects associated with skin disease. These include depression, a decreased sense of body image and self-esteem, sexual and relationship difficulties, and a general reduction in quality of life (Dungey & Busselmeir, 1982; Obermeyer, 1985; Porter et al., 1987; Papadopoulos et al., 1999). Indeed, research has shown that people with skin disease experience higher levels of psychological and social distress (Root et al., 1994), poorer body image and lower self-esteem than the general population (Papadopoulos et al., 1999) and higher avoidance of situations where their skin may be exposed (Rubinow et al., 1987). Leary and colleagues (1998) suggest that the degree of social anxiety depends on a person’s confidence regarding their ability to successfully manage the impression they make and it has been shown that social anxiety is a mediating factor between the severity of a disfiguring condition and an individual’s emotional reactions.

An eclectic group of skin disease outpatients reported that their lives had been affected by skin disease in many ways (Jowett & Ryan, 1985). They reported difficulties in their relationships and poorer employment opportunities due to their skin disease, not to mention the damage that they felt their skin disease had afflicted on their self-esteem. Furthermore, functional and interpersonal problems in the workplace, increased anxiety and lack of confidence were also cited. Many patients feel that their sexual relationships and ability to find a partner have also suffered due to their skin condition (Porter et al., 1990). Furthermore, a British survey of acne patients showed unemployment levels in acne participants to be significantly higher than control participants (Cunliffe, 1986).

There is also evidence for cross-cultural stigmatisation due to skin disease. A striking example of this is the case of onchocercal skin disease (OSD), a disfiguring skin disease mostly found in Africa and associated with river blindness (onchocerciasis). Through a series of interviews with OSD sufferers in five different African sites, it was concluded that attitudes towards stigmatising illnesses showed strong similarity over the geographical and cultural areas specified in the study (Vlassoff et al., 2000).

Perhaps one of the crucial myths that permeates the lay discourse on skin disease is that of the severity of the condition being in some way related to a fixed psychosocial morbidity as experienced by the sufferer. This myth can help to form a barrier between the patient and friends, family and health professionals when outsiders automatically assume that a small or invisible lesion of dermatitis should not affect the psychological health of the sufferer. Thompson and Kent (2001) note that there is considerable evidence to suggest that self-perceived appearance, the view from the inside, is actually limited in its relationship with the social reality of appearance (Ben-Tovim & Walker, 1995; Robinson et al., 1996; Kleve et al., 2002).

## Management

Psychosomatic management in dermatoses requires a perspective beyond the skin and its lesions. This means a more holistic perspective, with the use of anamnestic techniques and an adaptation of the physician/patient relationship. Many psychotherapeutic approaches, ranging from orthodox psychoanalysis to cognitive–behavioural therapy, biofeedback, behavioural conditioning and insight-orientated psychotherapy, have been employed in the treatment of dermatological disorders but the assessment of these psychological techniques in general has been inadequate (Van Moffaert, 1992). However, the incorporation of psychotherapeutic techniques into the domain of dermatology do generally improve patients' quality of life and at the least, do no harm. One of the principal problems with non-pharmacological treatments is that they lack the inherent appeal of drug studies to a scientific community. Drug studies allow the elucidation of chemical structures, physiological and biochemical processes, and so forth. Concrete constructs such as these allow definitive conclusions whereas non-pharmacological treatments allay a complexity of response that can be difficult to fully appreciate.

As mentioned, the series of changes that can affect individuals with visible medical conditions can be profound and there has been an increase in interest in the role of psychological therapy and visible medical issues in recent years. The practice of psychodermatology requires an eclectic approach and a monoform treatment of psychosomatic dermatosis is bound to be ineffective (Brown & Fromm, 1987). Problems that often exist in the current medical context is the lack of breadth in the knowledge of health professionals. General practitioners (GPs) often feel ill informed in the area of dermatology and dermatologists themselves can feel ill at

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ease with treatments that belong to the psychological field. However, the work that has addressed the application and efficacy of psychological interventions has shown that they appear to offer a useful adjunct to standard medical treatment.

## Theoretical models and psychodermatology

Contextualing a review of any discipline requires that the discipline be placed within a theoretical and historical framework, and this approach is appropriate for psychodermatology. By the 1950s, the incidence of contagious diseases had declined rapidly and non-contagious diseases were on the increase. These included diseases that are related to lifestyle variables such as lung cancer and heart disease. Improved hygiene, vaccines and general medical treatment led to longer-life expectancy and the effects of health-compromising behaviours such as smoking, drinking, alcohol and poor diet had a growing effect on health. As a consequence of the limitations of the biomedical model and the change in disease statistics, researchers in the fields of health, psychology and medicine had begun to focus on the biopsychosocial model, a model that posits the fundamental assumption that health and illness are consequences of the interplay between psychological, biological and social factors (Engel, 1977). The biopsychosocial model maintains that health and illness are caused by multiple factors and produce multiple effects (Taylor, 1999). Interestingly, however, this perspective was not necessarily novel with respect to skin disease since a systemic view of the condition began to emerge as far back as the late 19th century with the work of dermatologists like Tuke (1884) and Beard (1880).

## The diatheses–stress paradigm

Although we know that emotional factors can influence a wide range of medical conditions, we know less about why some people develop one disease in the presence of psychosocial stress while others develop no disease or a completely different set of symptoms. In order to understand this, it is necessary to understand the interaction between environmental and psychological variables in terms of an individual predisposition to a particular disorder. The diathesis–stress paradigm can sit as an adjunct to the biopsychosocial model (Meehl, 1962) and it focuses on the relationship between a predisposition to disease, the diathesis, and an environmental disturbance, the stress. With respect to skin disease, it has been suggested that sufferers inherit or gain a basic organ inferiority that will determine the results of psychological/biological upsets in such a way that autonomic activity may be directed towards the weak organ (Winchell & Watts, 1988). As regards dermatology, the weak organ is the skin.

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## Stress and dermatology

As far back as the 19th century, Hillier (1865), in working with eczema, implicated mental excitement, nervous debility and anxiety as the cause of these skin diseases. In 1982, Teshima and colleagues found that emotional stress had the capacity to influence the immune system to a great extent and that this would often manifest in cutaneous illness. They found that the tension in patients could lead to an enhancement of allergic reactions and these allergic patients were shown to improve with relaxation and autogenic training. There were also speculative implications for skin disease with the finding that the function of T-cells and the phagocytosis of macrophages were suppressed by induced stress. Furthermore, evidence of the strong relationship between the skin and the central nervous system (CNS) has been demonstrated by Ortonne and colleagues (1983) who noted that innervation of the CNS often produced blushing, perspiration and pallor.

Indeed, there has been considerable research that has investigated the role of emotional upsets antecedent to eruptions of skin disease with a number of conditions and consensus has suggested an association between stressful life events and the onset of skin conditions (Greismar, 1978; Invernizzi et al., 1988; Harper, 1992; Al'Abadie et al., 1994; Liu et al., 1996; Papadopoulos et al., 1998).

## About the book

This book is intended to provide material of interest for a range of health professionals, including psychologists, psychiatrists, GPs, nurses and dermatologists as well as any other professionals who work with dermatology patients. Indeed this multidisciplinary readership is the key context behind the creation of the book. The book has been developed by academic psychologists, psychiatrists, psychotherapists and dermatologists, and it has taken the specific skills of each of these experienced professionals in order to provide the knowledge base behind the specific chapters. As health professionals involved with dermatology patients, it is our responsibility to be aware of all facets of skin disease and the way that these different facets interact to create the experience of suffering that can result from skin disease. Time constraints, financial restrictions and organisational inertia mean that this broadening of knowledge to better understand the physiological, psychological and social is not always possible. If anything, it is the purpose of this book to use the shared knowledge of our different contributing experts to help to broaden our perspective as health professionals both generally and specifically in the hope that skin disease patients receive a greater level of service in whatever health context they use.

In Chapter 2, Dr Leslie Millard, a Dermatologist from the University of Nottingham, discusses the multidisciplinary relationship between the physiological,

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psychological and social aspects of skin disease and the way that these factors can interact to influence the course of the disease is discussed. A treatment of recent research and approaches in the field of psychoneuroimmunology and how these relate to skin disease are discussed.

The psychiatric comorbidity in dermatological disorders is often one of the most important indices of the overall disability associated with these conditions and it is well established that significant psychiatric and psychosocial comorbidity is present in at least 30% of dermatology patients. Chapter 3 looks at the psychological morbidity associated with skin disease. Dr Madhulika Gupta, a Psychiatrist from the University of Ontario with expertise in the psychosocial aspects of skin disorder, highlights the relationship between dermatological disease and psychiatric comorbidity. This chapter focuses on the results of research on the relationship between skin disease and such psychosocial constructs as depression, suicidal ideation, social anxiety and body dysmorphic disorder.

In Chapter 4, Dr Gerry Kent from the University of Sheffield focuses on the stigma associated with disfigurement and skin disease particularly. Dr Kent, a Psychologist with a particular research interest in the stigma associated with vitiligo, highlights the myths and prejudice felt by those who are visibly different. By addressing the types of stigmatisation that people encounter, the content and effects of these experiences, the reasons why stigmatisation occurs and the ways in which we might reduce stigmatisation as well as a consideration of future research possibilities, Dr Kent comprehensively addresses the different ways in which people can feel stigmatised and the responses to this stigma.

Chapter 5 elaborates on factors that impact upon the adaptation and coping process. Dr Andrew Thompson, a Clinical Psychologist from the University of Sheffield who has published widely on the topic of skin disease and coping, discusses the various behavioural and cognitive changes that may accompany the onset of a skin condition. This chapter reviews the literature pertaining to adjusting to life with a chronic dermatological condition and details the factors that play key mediating roles in explaining individual variation in coping and adjustment.

The role and significance of intimate relationships in adjusting to skin disease is a neglected area in dermatology, despite evidence that partners are usually the most important source of support when facing ill health. Previous chapters have described the emotional and psychological effects of skin disease on the individual but skin disease often has an impact on relationships and Chapter 6 considers this impact and focuses on some of the relationship contexts in which difficulties regarding the skin condition may arise. Issues covered include the impact of skin disease on relationships, appearance and physical attraction, communication problems and sexuality. This chapter is contributed by Litsa Anthis from London