



## Getting Under the Skin: The Inscription of Dermatological Disease on the Self-Concept

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### Abstract

*Psychological factors have long been associated with the onset, maintenance and exacerbation of many cutaneous disorders (Newell, 2000, p. 8; Papadopoulos, Bor & Legg, 1999, p. 107). Chronic cutaneous disease is often visible to others so that social factors in coping and adjustment are thus highly relevant (Papadopoulos, et al., 1999, p. 107). Psychological factors tend, however, to be overlooked in the dermatological treatment domain when the skin problem is not regarded as life threatening (MacGregor, 1990 as cited in Papadopoulos, et al., 1999, p. 113). In 2004, at a meeting of the Editorial Board of Dermatology Nursing, the need for studies presenting the patient's perspective on living with a skin disease was discussed. It was thought that qualitative exploration of the patient's experience of cutaneous disease would provide medical and mental health care professionals with valuable insights and important information to help improve dermatology patient care (Hill, 2004, p. 399). More specifically, Papadopoulos et al. (1999, p. 122) posit that qualitative exploration of dermatological patients' lived experience might help provide insight into the efficacy of coping strategies, the need for psychological counsel, and also the need for a more holistic understanding of this patient population rather than maintaining a dichotomous focus on either the mind or the body.*

*Research in the field is currently characterised by (a) a predominance of quantitative studies, the design of which results in inevitable loss of in-depth information regarding the experiential world of sufferers of cutaneous disease (Hill, 2004, p. 399; Papadopoulos, et al., 1999, p. 122), and (b) a dearth of studies investigating the impact of disfiguring skin conditions on the self-concept. In order to address this lack, and simultaneously to contribute towards mapping the psychodermatological terrain in need of qualitative exploration, this paper attempts to integrate the findings of relevant studies in the fields of both dermatology and psychology, with specific focus on women suffering from psoriasis, a common chronic disorder of the skin, and the impact of this on the various dimensions of self. The primary aim of this paper is, however, to prompt qualitative - and, in particular, phenomenological - research in the area of body disfigurement and self-concept in order to elucidate the lived experiences of people afflicted with disfiguring dermatological conditions, and as such to promote necessary change in the therapeutic domain.*

### Introduction

This paper focuses on women who live with common (in the sense of frequently occurring) chronic

disfiguring dermatological disorders, with specific reference to women who suffer from psoriasis and the impact of this on their self-concept. The need for qualitative and, in particular, phenomenological

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exploration of the experiential dimensions of such disorders is emphasised in the light of the perceived need for medical and mental health care professionals to glean deeper insight into the human experience of those afflicted with conditions that are too often treated as merely skin-deep.

As a multi-dimensional construct, self-concept is defined in accordance with Van Deurzen-Smith's (1997, p. 98) dimensions of self, namely: (a) the physical, natural and material dimensions; (b) the social, cultural and public dimensions; (c) the private, personal and psychological dimensions; and, finally, (d) the spiritual, interpretive and ideological dimensions. Self-concept is further conceptualised as both a stable trait and a fluctuating state variable (Stake, Huff & Zand, 1995, p. 223).

The relationship between the physical body and the natural environment connotes an individual's most fundamental mode of interaction. Naturally, then, as complex bio-socio-psycho-spiritual organisms, we are conjoined to the world around us in everything we are and do (Van Deurzen-Smith, 1997, p. 103). Accordingly, Van Deurzen-Smith (1997, p. 106) posits that the sort of body we have is instrumental in determining how we come into contact with the world. Thus, although chronic skin conditions are not usually life threatening, the resultant disfigurement of the body can negatively impact on one's sense of being in relation to the world.

This paper examines the relevant literature in four areas of concern. First, it examines the literature on commonly reported psychological difficulties associated with disfiguring skin conditions; second, and with specific reference to women who suffer from psoriasis, commonly reported social experiences of persons with disfiguring skin disorders are examined; third, the literature on psycho-neuro-endocrine-immunology is explored in so far as it points to the importance of treating the person as a whole; and, finally, the need for and importance of qualitative research in the field of psycho-dermatology, and methodological procedures capable of elucidating the world of the subjects, as they live and experience it, is discussed.

### **The Psychological Impact of Disfiguring Skin Diseases**

According to the self-schema theory proposed by Markus (as cited in Stake, Huff & Zand, 1995, p. 224), persons hold internal cognitive generalisations about the self (i.e., self-schema) that guide the processing of self-relevant information. In terms of this theory, self-schemas enable individuals to extend beyond information currently available to interpret

meaning in a manner consistent for the self across time and circumstance.

Substantial evidence suggests that people more readily accept and assimilate information that is consistent with their concept of self (Shrauger & Kelly, 1988; Swann, Griffin, Predmore & Gaines, 1987; Sweeney & Wells, 1990 as cited in Stake et al., 1995, p. 224). In this regard, self-schema theory advocates that temporary shifts in self-evaluation in response to events are consistent with the individual's level of trait self-esteem (the affective facet of self-concept) (Stake, et al., 1995, p. 224). Accordingly, irrespective of whether low self-esteem is primary or secondary to a disfiguring skin condition, it follows that, when self-esteem is low, people who suffer from disfiguring and debilitating skin conditions may make more pervasive negative shifts in self-evaluation (Stake, et al., 1995, p. 225) than would persons who do not suffer from cutaneous disease.

Given this insight, it might be the case that many persons suffering from a disfiguring skin disorder fall within a high-risk group for the development of disturbances of the physical, social, psychological and spiritual dimensions of self, and most especially so when trait self-esteem is low. Disturbances of this kind can manifest in severe psychopathology with significant mental health implications (Stake, et al., 1995, p. 226). Cyclically, manifest psychological difficulties aggravate dermatological disorders by decreasing the immune response and, consequently, the psychopathologic experience is intensified (Linsteadt, 2002, p. 21). A study by Stake et al. (1995, p. 235) shows that, when self-esteem is low, the meaning of negative self-relevant information is more likely to be generalised to non-related aspects of the self and to the self as a whole. In line with the observations made by Stake et al. (ibid), it might be hypothesised that, when experienced as a negative event, skin disorders may serve to reinforce and maintain this downward spiral in psychological health.

### **Influencing the Psychological Dimensions of Self**

Psychological factors have long been associated with the onset, maintenance and even the exacerbation of dermatological disorders (Papadopoulos, et al., 1999, p. 107). Although this is recognized in the dermatological and psychiatric fields, many medical and mental health care professionals either overlook or ignore resulting psychological difficulties, particularly if the skin problem is not serious or life threatening (MacGregor, 1990 as cited in Papadopoulos, 1999, p. 113; Newell, 2000, pp. 5-38). According to Hughes et al. (1983 as cited in Papadopoulos et al., 1999, p. 108), there is much evidence that suggests a higher prevalence of

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psychiatric disorders in dermatological patients than in either the general population or general medical inpatient population.

Although it remains unclear whether psychological problems are causally related to dermatological conditions, or whether, in fact, a linear relationship exists between the two, what is apparent is that disfiguring skin conditions and psychopathology, for many individuals, go hand in hand. Stress, for example, is a psychological factor associated with both the onset and exacerbation of cutaneous disease. A study by Obermeyer (as cited in Papadopoulos, 1999, p. 111) found a sizeable proportion of dermatological patients to be clinically depressed.

In a study by Watson (2003, pp. 43 & 62) of 28 women suffering bodily disfigurement due to disorders of the skin, results revealed significant differences for participants in areas of emotional stability and physical appearance. Using the *Self-Description Questionnaire III*, all participants rated the private and physical dimensions of self-concept (such as sociability and being physically attractive) as qualities and features of the self that were very important to them. Significantly, however, and as a consequence of suffering from a disfiguring and debilitating skin problem, the participants did not feel that sociability and physical attractiveness were accurate descriptions of them. Furthermore, when compared to how they felt about themselves prior to the onset of cutaneous disease, participants in this study felt less physically and sexually attractive and suffered from low self-esteem. Such observations add support to the notion of Stake et al. (1995, pp. 237-238) of there being an association between negative self-evaluation and low self-esteem. As Francis (2002, p. 115) states aptly, illness and disease is an intrusion of the embodied self and inscribes the body so that the mind and body can no longer be seen as separated.

Although the physiological mechanisms through which diseases of the skin act are different, they share a common denominator in that they are often chronic and visible. Thus, many depressive symptoms encountered by persons with these conditions may be a response to, rather than a cause of, the illness (Van Moffaert as cited in Papadopoulos, 1999, p. 111).

### **The Social Impact of Disfiguring Skin Conditions**

As noted by Van Deurzen-Smith (1997, pp. 98-99), body image forms one dimension of the physical self (of which the natural and material self are subcategories), and the physical self is only one dimension of self-concept. The many dimensions of self represent a conglomerate of one's knowledge,

assumptions and feelings about oneself, influenced by not only mass media, but also the dictates of genetics, culture, religious teachings, family, tradition and so forth. Whilst some aspects of self remain stable for years, other aspects change from one moment to the next. In recognising self-concept as a construct that is highly complex, central to mental processes and unique to the individual in relation to his or her meaning-making and experiencing, exploration of the construct within the field of psychology has increased (Hattie & Marsh, 1996, p. 38).

In terms of positive and negative self-evaluation, research has shown the physical self to be integral to a woman's overall concept of self (Jacobs & Very as cited in Theron, Nel & Lubbe, 1991, pp. 973-983). It is perhaps unfortunate that one's physical identity is so stereotypically ascribed by the attitudes of society. Where the physical and the social aspects of existence are rendered unsafe (e.g., by social stigma), a prematurely defined self may develop. In extreme instances where the entire self-image of the person is based upon his or her relation to the material or public world, such persons may develop psychopathic tendencies if the body is considered to be foremost in importance, or sociopathic tendencies if the ego is most important to the person (Van Deurzen-Smith, 1997, pp. 118-119).

### **Influencing the Social Dimensions of Self**

The sort of body we have is an instrumental primary determinant in how we come into contact with the world. Although a boundless range of modulation is possible with the body we possess, it must be recognised that we have limited range in terms of the type of body that we are (Van Deurzen-Smith, 1997, p. 106). In instances of suffering from a chronic disorder of the skin, many women may feel entrapped within an unfamiliar body. The severity of this experience might, in part, be a consequence of following a body image hype constructed by public and private mass media. Industries in fashion, cosmetics and sports ensure conformity to their trend setting and established norms by targeting public perception through a range of products and expensive advertising. Skin disorders do not conform to the social ideal projected by the mass media (Newell, 2000, p. 1). Consequently, negative self-evaluations might be the experience of many women who live with disfiguring and debilitating dermatological conditions.

The effects of 'unusual appearances' have preoccupied people for centuries. During the Elizabethan Age, Sir Francis Bacon (as cited in Newell, 2000, p. 57) asserted that "deformed people are commonly vengeful - returning in coin the evil that nature has visited upon them". Although clearly

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an anecdotal opinion from well before the beginning of systematised examination of disfigurement, it is an interesting early example of the negative stereotyping of disfigured people. The use of the word “evil” in this context is likewise instructive, connoting the commonly held belief that physical beauty is good and deformity is bad. Age-old adages of this nature continue to persist as aspects of attitude in contemporary society (Newell, 2000, p. 57).

In a study by Papadopoulos et al. (1999, p. 113) on psychological factors associated with cutaneous disease, eighty percent of patients indicated that they were embarrassed and self-conscious about their appearance and felt that people were more likely to stare at them. Although such experiences might be thought commonplace, such perceptions affect a person’s interpersonal and social behaviour (Lansdowne, 1997 as cited in Papadopoulos, et al., 1999, p. 115). According to Papadopoulos et al. (1999, p. 115), the social and cultural significance of skin serves to influence how positively or negatively we think others appraise us. Furthermore, many researchers have suggested that the effects of feeling stigmatised may alter a person’s cognitive processing, leading him or her to perceive even benign responses as hostile. Thus, it would seem that people with visible cutaneous conditions tend to be perceived as different from those whose appearance is unremarkable and, similarly, perceive themselves as different.

To appreciate what it might mean to live with ‘difference,’ it should prove enlightening to consider the common experiences of women who suffer from psoriasis.

### **Psoriasis Defined**

Psoriasis is a chronic inflammatory skin disorder that causes considerable impairment of the sufferer’s quality of life. While the underlying causes are not known, the immediate cause of psoriasis is the rate of growth and differentiation of the epidermis (the outer layer of the skin). In unaffected skin, the epidermis is renewed approximately every 28 days. With psoriasis, however, the epidermis is renewed every four days - a process referred to as hyper-proliferation. The effects of hyper-proliferation are anatomically disfiguring, resulting in psoriatic plaques from the thickening and a reddening of the skin; the sloughing of silvery scales; pruritus (severe itching) of the affected areas; and a thickening and yellowing of the fingernails and toenails. The surface area of the body affected varies from small patches to total skin coverage (Young, 2005, pp. 15-16). Although psoriasis is a frequently observed disorder of the skin, no statistics in this regard could be found for South Africa.

### **Women, the Experiencing Self and Psoriasis**

Given the importance attached to the female anatomy in contributing to a woman’s concept of self, deformity of a body part may well have far reaching consequences. Various studies have revealed, for example, that chronic disorders of the skin, such as psoriasis, can affect a woman’s concept of self physically, emotionally, socially and spiritually (Kew, Nevin & Cruickshank, 2002, pp. 193-196; Newell, 2000, pp. 103-104; Watson, 2003, pp. 62-63; Young, 2005, pp. 16-17).

A survey conducted by Gupta and Gupta (1995, pp. 240-243) found sufferers of psoriasis to experience external shame (fear of negative evaluations and stigmatisation) as well as internal body shame (negative self-evaluations and self-focused feelings). This observation connotes the involvement of the social, cultural and public dimensions of self-concept, as well as the private, psychological and interpretive dimensions of self-concept. Such findings support the self-schema theory discussed earlier as well as the findings by Stake et al. (1995, p. 235) with regard to the generalisability of meaning to non-related aspects of self. What is not clear from the survey, however, is the meaning-making experience of each patient that resulted in the social fears and negative evaluations of self evidenced.

What does seem to be apparent from the dermatological studies referred to thus far, is that a disturbance in one dimension of self (e.g., the physical self-concept) will have a trickle down effect on other facets of self (e.g., the private, social and spiritual dimensions), differing only by degree. In a study by Gupta and Gupta (1996, pp. 1030-1034) on women with psoriasis, it was noted that disturbances in self-concept, such as body shame and self-alienation, contribute to the onset of clinical psychopathology such as depression, anxiety, unfocused anger and obsessional behaviours.

Similarly, in a study by Choi and Koo (2003 as cited in Young, 2005, p. 16), the impact, in terms of quality of life, of psoriasis on the psychological and emotional dimensions of self, correlates strongly with disease severity and visibility, and is comparable to that experienced by sufferers of more chronic diseases such as cancer, heart disease and clinical depression. Psoriasis is persistent, unpredictable and stressful over longer periods of time than more serious (i.e., life-threatening) illnesses (Young, 2005, p. 18). According to Van Deurzen-Smith (1997, p. 108), some people never learn to accept the way they are, with many individuals requiring professional help in describing their bodily being in relation to the world and to come to terms with the positive and negative aspects of self.

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The observation of Van Deurzen-Smith (1997, p. 108) that some people never learn to accept the way that they are, begs the question “Why not?” In considering the studies cited, all make reference to quantitative analysis, with the interpretation of the results based on the outcome of the psychometric measures utilised. In that in-depth descriptions of the experiential world of the sufferers of cutaneous disease are thus not provided for, what is suggested is the need for future research that is descriptive and more focussed on a particular self-dimension as opposed to self-concept generally.

Phenomenological exploration of the patient’s experiential world might help to elucidate the patient’s perception of suffering from cutaneous disease. A phenomenology of perception alters the direction of focus from understanding perception as a way in which the world is perceived, to the world of the patient being that which is perceived. Understanding the lived world (*Lebenswelt*) of the patient takes on the renewed significance of including the role of consciousness in the study of human behaviour, reducing distance between the person and the lived experience of the person (Valle, King & Halling, 1989, pp. 9-10).

Supporting the need to elucidate the experiential world of persons who suffer from cutaneous disease, Lotter (1997, p. 18) argues that

the function of the brain can be seen as a complex phenomenon wherein, while consisting of many different parts, these constituting parts form a complex whole with different characteristics. Attempts to analyse the whole will thus fail if a reductionist approach is used.

This accords with the phenomenological rejection of reductionism and perspective on the world as a totality of meanings, in which human beings discover meaning rather than confer meaning on structures that are essentially meaningless. According to Ivey, Ivey and Simek-Downing (1986, p. 269), existential phenomenology is

based on the belief that each person sees the world uniquely and constructs his or her own reality through transactions with the world and others. We can know ourselves only through our relationship with others. ... It is centrally concerned with examining the meaning of life and our place in the world.

In the light of the above, phenomenological exploration of how cutaneous disease impacts on the self-concept might also help elucidate how many people who live with a disfiguring skin disorder manage to cope remarkably well psychologically and socially, and why many do not. For the present, however, the way in which positive and negative self-evaluations and meaning-making in one’s experiential world impacts on the physical dimensions of self is perhaps best elucidated by studies on psycho-neuro-endocrine-immunology and cellular communication (Linsteadt, 2002, pp. 10-21; Pert, 1998, p. 190).

### **Psycho-neuro-endocrine-immunology**

Although the science of psycho-neuro-endocrine-immunology has shed light on the interconnectedness of our emotions and psyches with our nervous, hormonal and immune systems (Linsteadt, 2002, p. 20), the medical model has tended to reduce the body to mechanisms and measurements of technical objectivity that deny the person’s identity as anything other than ‘patient’ (Francis, 2002, p. 115). According to Linsteadt (2002, p. 20), psycho-neuro-endocrine-immunology raises significant questions in respect of the preoccupation of orthodox medicine with treating symptoms or applying medication that masks symptoms.

The physiological nature of cellular communication suggests an interconnectedness between the brain and the body such that physical disease is seen to affect physical, psychological, social and spiritual processes and vice versa (Pert, 1998, p. 187). According to Pert (1998, p. 190), given the involvement of molecules of emotion in the process of viruses entering the cell, one can deduce that emotional health impacts on physical health in terms of whether or not the individual is susceptible to viral infections and vice versa. It is this conceptual framework that provides the point of departure for understanding the role that emotions play in healing the body.

Griffith and Griffith (1994, p. 44) postulate that, in its wisdom, the body communicates a story in pre-symbolic meaning that circumvents the use of words - and of which skin disorders might be part. According to the authors, trauma mirrors the isolation and entrapment felt by the patient when no options for emotional resolve, verbal or otherwise, seem available. In this way, the body can become a metaphor, an unspoken language that presents itself physically when the verbal expression of emotion is inhibited.

Psycho-neuro-endocrine-immunology focuses on a web of relationships between the mind and the nervous and immune systems, and reflects a

sophisticated interplay of molecular biology and the more abstract aspects of psychology. The emergence of the biopsychosocial model and psycho-neuro-endocrine-immunology both prompted and facilitated the examination of medical problems at cellular level (Pert, 1998, pp. 190-191). Pert (1998, p. 137) posits all changes within the physiological state to be accompanied by an appropriate change in the mental/emotional state.

For Pert (1998, p. 137), the body is the unconscious mind, with the body acting as a reservoir for repressed trauma. In this way, there exists an intricate twining of emotions and bodily sensations within a bi-directional network in which each can alter the other. According to Pert (ibid), more recent discoveries bring to the fore the storage of memories not only in the brain, but also within psychosomatic networks that extend into the body. This, notes Pert (ibid), fits nicely with Paul Ekman's (as cited in Pert, 1998, p. 145) formulation that each emotion is experienced throughout the organism and not just in the head or the body as separate entities.

Pert (1998, p. 187) extends the idiomatic inference of 'the power of mind over body' to assert the notion of the mind becoming the body, and mind and body hence being one and the same. In line with the present author's beliefs, Pert (ibid) asserts that the process of communication, in terms of the flow of information throughout the whole organism, is evidence that the body is the actual outward manifestation, in physical space, of the mind.

The interplay between mind and body is important in the overall treatment and management of women and men who live with body disfigurement as a consequence of suffering from a disorder of the skin. Often, the focus of therapy is limited to the parts of the body displaying symptoms (Francis, 2002, pp. 115-117; Linsteadt, 2002, p. 20; Pert, 1998, p. 274) rather than encompassing the whole self. How people who live with disfiguring skin conditions interpret their experiencing self will impact on how they read the world and, in turn, are read (Francis, 2002, p. 115). Metaphorically, the skin is the door to physical and psychological problems and process, and medical and mental health care professionals would do well to heed this (Papadopoulos, et al., 1999, p. 108).

Given the discussions thus far, the benefits of qualitatively descriptive exploration of the experiential world of bodily disfigured individuals may have become clearer. Whilst by no means discounting the importance of quantitative investigation, the world cannot, as Francis (2002, p. 115) posits, be divided up into sites of pathology and

non-pathology. The human experience is so much more, as the section that follows aims to highlight.

### **The Need to Explore the Human Experience**

Irrespective of the severity of body disfigurement, whether this is defined clinically or subjectively, disfiguring dermatological conditions, such as psoriasis, can be psychologically and socially devastating (Koo & Lebwohl, 2001, pp. 1873-1878; Thompson & Kent, 2001, p. 668; Watson, 2003, p. 15). Descriptive research that elucidates the full experiential reality of people who live with disfiguring cutaneous disorders, and in particular the impact thereof on the self-concept, is, however, limited in medical and psychological literature.

As far as can be ascertained, there appears to be a dearth of descriptive research exploring the experiential world of persons who suffer from more common cutaneous diseases, such as warts or psoriasis, in South Africa. More specifically, South African studies describing the impact of common chronic cutaneous disease on the self-concept of sufferers were not found.

According to Newell (2000, pp. 5-38), a lack of qualitative investigation in this field might be a consequence of the frequency with which certain skin ailments manifest. To explicate, Newell (ibid) makes reference to the port wine stain syndrome, a frequently observed birth defect of the skin. Newell (ibid) suggests that qualitative exploration of the experiential reality of people who suffer from this syndrome might provide in-depth insight into the psychological trauma experienced and also the coping mechanisms utilised. Newell (ibid) further suggests that the lack of qualitative exploration of this syndrome is a consequence of the frequency with which the port wine syndrome is experienced in treating medical institutions and also the fact that, although severely debilitating emotionally for many sufferers, the port wine syndrome is not considered a serious life-threatening illness.

The literature search conducted on databases such as Dissertation Abstracts Online, ProQuest, PsychInfo, ScienceDirect, and South African Studies found many articles on self-concept and dermatological disorders respectively. There was a dearth, however, of research focusing on self-concept and dermatological disorders as interrelated. With particular reference to self-concept and psoriasis, studies on the former tend to focus predominantly on quantitative analyses of self-concept variables, whereas studies on psoriasis focussed largely on the physiology of psoriasis and pharmacological therapies. Quantitative studies investigating dermatological disorders focussed

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primarily on disturbances in body image (a uni-dimensional mental construct of the self) and self-esteem. The effects of mental attitude on skin disease were researched largely using objective measures. Qualitative exploration of the experiential reality of people who live with disfiguring dermatological disorders seems limited.

Due to the limited reference in the literature to qualitative research exploring the human experience of skin disorders, much of the experiential world of sufferers is silenced, with potentially disempowering impact (Francis, 2000, pp. 115-117). As a complement therefore to quantitative investigation, phenomenological description of the impact of disfiguring dermatological disorders on the various dimensions of the individual's self-concept would better position medical and mental health care professionals to address the needs of these patients and their families. A failure to integrate the psychological, social and spiritual aspects of self with bio-physiological processes masks possible curative benefits (Linsteadt, 2002, p. 8).

### **Qualitative Research as a Means of Probing Beneath the Skin**

According to Papadopoulos (1999, p. 112), the ultimate development of a more holistic approach to psychotherapeutic interventions requires that research investigating the experiences of people living with disfiguring dermatological conditions account for the personal, social and physical aspects of skin disease and seek to integrate these aspects with factors such as cultural beliefs, family systems and patient care systems. The multifaceted interaction between psychology and dermatology is becoming ever more evident and opens up the possibility of a whole sub-speciality of psycho-dermatology, with research in both fields underscoring the variety and extent of connections between the two (Bradbury, 1995 as cited in Papadopoulos, 1999, p. 112; Partridge, 1994).

Primarily, dermatological studies are quantitative and disease-specific. We know much about the physiological make-up of skin disorders, the interactions of topical applications and the side effects of pharmacological interventions. Some studies mention depression, guilt and body shame as secondary experiences and the impact of these on body image. What we do not know much about in this instance is the human experience, as described by the sufferer, of individuals who live with a disfiguring skin condition (Newell, 2000, pp. 68-75). Furthermore, we know little about why some people who live with disfiguring cutaneous conditions cope reasonably well and some do not. Descriptive research would allow for the human experience to

unfold from the subject's perspective. In addition, the multifaceted dimensions of self-concept would allow for a more detailed exploration of the person as a whole (Hattie & Marsh, 1996, pp. 38-90) and, ultimately, provide in-depth insight into the mind/body human experience (Linsteadt, 2002, p. 20).

In becoming more aware of how skin disease impacts on the various dimensions of self-concept and how many disfigured individuals interpret their world and meaning-making experience, medical and mental health care professionals can network as a team united in helping to bring about positive change within any one individual when difficulties manifest. According to Peck (1990, p. 14), among the greatest truths in life is that, unless we learn to accept, understand and make meaningful life, then life will be experienced as a road of much tribulation. For many persons, the trauma of living with body disfigurement makes positive meaning-making too difficult to walk the path alone, plunging them deeper and deeper into the darkest pit.

The meaning-making of one's experiential world is an individual process. According to Einstein, Podolsky and Rosen (as cited in Spinelli, 1989, p. 7), the meaning that individuals ascribe to events remains implicit in their experience of reality. It cannot, however, be deduced that the meaning arrived at is a true or accurate reflection of reality. In this regard, phenomenologists propose that our experience of the world is made up of an interaction between the raw matter of the world and our mental faculties. Neither is perceived in isolation but rather as interconnected and interacting, with each individual adding a number of variables derived from her or his individual life experiences. Despite their interconnected and interactive situatedness, people construct individually unique interpretations of their experiential reality (Einstein, et al., as cited in Spinelli, 1989, pp. 8-9).

### **Voicing the Silenced Dialogues Qualitatively**

Humans experience suffering differently and this difference cannot be captured quantitatively. Privileging no single methodology over another, qualitative research approaches are interdisciplinary, trans-disciplinary and, not infrequently, counter-disciplinary crosscutting the humanities, social and physical sciences. With its emphasis on meanings and processes, qualitative research illuminates the manner in which the social world is constructed and made meaningful (Denzin & Lincoln, 1994, pp. 9-11).

From a qualitative perspective, the richness and profundity of human reality is seen as closely related to the structures and meanings of natural language. Broadly, qualitative research is identified with a

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commitment to the logic of natural language as the preferred mode of understanding human experience. Descriptive research refers to all those inquiries whose aim is to provide a neutral, close and thorough account of the topic under investigation. Accordingly, such studies seek to discover the essential attributes of a phenomenon and then express the findings that emerge in verbal portraits (Neuman, 1997, pp. 329-330).

### **Phenomenology as a Qualitative Method of Describing the Individual's Experiential World**

Phenomenology refers to a philosophical movement that has received its most persuasive impetus, formulation and defence from German philosopher Edmund Husserl. Husserl's phenomenology takes, as its *modus operandi*, Cartesian attention to the primacy of first-person experience and the Kantian search for basic *a priori* principles (Solomon, 1980, p. 1).

From a phenomenological perspective, it is assumed that the creation of meaning emerges both for the individual and for others through their experience of the world. The primary focus of phenomenological exploration is on the world of everyday experience as expressed in everyday language and pure phenomena, autonomous of and prior to reflective interpretation (Valle, et al., 1989, pp. 9-10). In its emphasis on experiential reality, the focus of phenomenology thus accords directly with the need pointed to by Hill (2004, p. 399) and Papadopoulos et al. (1999, p. 122) for more in-depth descriptive exploration of patients' perspective on their personal experience of living with a disfiguring dermatological disorder.

In essence, phenomenology is concerned with the relationship between the reality that exists outside of the mind (objective reality) and the variety of thoughts and ideas each individual has of reality (subjectivity) (Spinelli, 1989, pp. 28-29). Given directly and immediately in human experience, the *Lebenswelt* (life-world) of the person becomes the point of departure of the phenomenological psychologist. The life-world is the beginning, the foundation upon which phenomenological thought is built. The life-world is co-created in the dialogue of person and world (as cited in Valle, et al., 1989, p. 9). *Lebenswelt* is prior to and the foundation of reflective thought, and as such pre-reflective in nature. Thus, although independent of knowledge derived from reflective thought processes, *Lebenswelt*, being pre-reflective, is indispensable as a point of departure for all knowledge.

Through description the pre-reflective life-world is brought to the level of reflective awareness where it manifests itself as psychological meaning, as such rendering phenomena accessible to understanding

(Valle, et al., 1989, pp. 9-10). Within the conceptual framework of phenomenology, all phenomena experienced by human beings are constructs, formed as a result of the invariant process known as intentionality - the *noema* (that which we experience or the 'what' towards which attention and focus is directed) and the *noesis* (the mode of experiencing, the referential element of experience or mode of 'how' through which we define an object). Each person's experience contains commonly shared variables; however, as a consequence of the unique experiential variables in each of our lives, no individual experience can fully be shared. Most basically, then, phenomenology presents itself as a science of individual experiencing, in which all knowledge is held to be rooted (Segal, 1999, p. 31; Spinelli, 1989, pp. 28-29).

Phenomenological exploration can help capture the cycle of self-concept that becomes destabilised and then reconstructed (Hormuth, 1990, p. 69) in persons living with a disfiguring condition of the skin. According to Rogers (as cited in Stevens, 1976, p. 51), there are two primary sources of self-concept. One is the person's experience - an awareness of that which is experienced as joyful or painful and of what one can and cannot do. The other comprises the evaluations of self by others - the definitions of self imposed by parents and other significant others and the values that are taken over from them. Development of self-concept is not just the slow acceleration of experiences, conditionings and imposed definitions, but a configuration. Alteration to one aspect of the self can completely alter the nature of the whole.

Hill (2004, p. 399) suggests that, with many studies looking at quality of life issues for patients with skin disorders, perhaps it is time that we heard the patient's perspective. As phenomenological research appreciates, our perspective as practitioners is only our own reality, not the patient's. Accordingly, a phenomenological approach studies experiences, with the "aim of bringing out their essences, their underlying reason" (Pivcevic, 1970, p. 11). Specifically, phenomenology is primarily concerned with understanding and describing human behaviour from the "actor's" perspective, and thus becomes an examination of the world as it is experienced (Bogdan & Taylor, 1975, p. 2).

Phenomenological research has the potential to provide invaluable insight into the deeper levels of the experiential reality of persons living with a disfiguring skin disease. In understanding the mechanisms and thought processes guiding the positive and negative evaluations of the various dimensions of self in patients suffering from

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disfiguring skin disorders, medical and mental healthcare practitioners may better appreciate the importance of teamwork through networking, and be provided with a framework within which to integrate more effective methods of treatment and therapeutic intervention in their aim to treat the whole person.

### Concluding Remarks

Drawing primarily on the findings of quantitative studies, this paper has attempted to integrate the field of dermatology with psychology in highlighting the impact of common, chronic, disfiguring and debilitating cutaneous disease on the self-concept of the sufferer, with specific focus on women who suffer from psoriasis. Self-concept was defined in accordance with Van Deurzen-Smith's (1997, p. 98) dimensions of self and conceptualised as both a stable trait and a fluctuating state variable (Stake, Huff & Zand, 1995, p. 223).

Individuals are made up of multiple selves that combine to create an infinitely unique self (Mahoney, 1991 as cited in Watson, 2003, p. 58). The individual can be seen as a system, which is open, non-linear, and dynamic and is characterised by a dialectical interplay with the world. The individual is ever changing and adapting to internal and external demands. In dealing with the demands of life, the person, as a dynamic system, is in a constant state of process (Butz, 1998 as cited in Watson, 2003, p. 58). The self constantly attempts to organise and reorganise its patterns of action and experience in relation to engagements with the world, and this necessarily entails biopsychosocial and spiritual change (Van Deurzen-Smith, 1997, pp. 100-102).

Change is endemic to human life, is ongoing and occurs at both surface and deeper levels of being (Neimeyer, 1995 as cited in Watson, 2003, p. 58). This is most profound in illness-associated body changes and when disease leaves the body in some way disfigured (Watson, 2003, p. 59). The view of skin disease as a handicap is not often recognised in the general population and people with skin disorders often face trivialization of their distress, which can further exacerbate the intensity or seriousness of feelings associated with their illness (Papadopoulos, et al., 1999, p. 113).

When something goes wrong with the physical self, the taken-for-granted body can become what Toombs (as cited in Stam, 1998, p. 14, 210) describes as "inescapable embodiment". Encapsulated within the unfamiliar body, changes that impact on the physical, psychological, social and spiritual dimensions of self can be experienced as alienating, and medical and mental health care professionals need to be cognisant

of this. For too long, say Johnson and Lakoff (as cited in Stam, 1998, pp. 210-212), medical professionals and psychologists have ignored the body when considering psychological health, inferring that the embodied nature of the organism that thinks plays no role in the nature of what is or what can be thought. By restoring the body to the mind, experiential realism intends to provide an improved understanding of the integratedness of human experience.

In South Africa, there exist many dermatological conditions that result in body disfigurement, with a number of studies noting the loss of femininity and the existence of self-concept disturbances, in one respect or another, to be the experience of many women who live with body disfigurement of some kind (Francis, 2002, pp. 109-116; Newell, 2000, p. 108; Watson, 2003, p. 1). Problematic, however, is that, as an area largely unexplored, the lived experience of the impact of body disfigurement on the self-concept of individual sufferers of disfiguring diseases and conditions remains silenced. Furthermore, the coping strategies utilised, that might elucidate why many dermatological patients cope reasonably well and others do not, are unclear.

In a study by Watson (2003, p. 59) of 28 South African women living with body disfigurement of some kind, 92.3% of the participants felt the need to join or form support groups and engage in group therapy as a means by which to voice, and make meaningful, their traumatic experiences. According to Orbach (as cited in Stam, 1998, p. 8), a woman's body is her communication system, her methodology for emancipation. Although the idea of the body as having an expressive function is by no means new, the claim that this capacity is fundamental to an individual's conception of self presents novel challenges within the disciplines of medicine and mental health. Similarly, and viewing the embodied self as a '*corpus-sujet*,' Harry Kempen (as cited in Stam, 1998, p. 8) posits body topics to challenge medical and mental health care professionals to reconceptualise their focal field in a manner that incorporates psychotherapeutic intervention in the treatment of the whole person.

The possibilities for phenomenological research in the emotionally charged and dynamic domain of body disfigurement are infinite. Furthermore, it is anticipated that exploration of this kind will help highlight a need for networking between medical and mental health care professionals in order to guide bodily disfigured individuals towards healthy meaning-making of their beingness in the world. It is possible, according to many psycho-neuro-endocrine-immunology studies on the interconnectedness of our emotions to our nervous, hormonal and immune

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system, that by treating the whole person (body and mind) numerous therapeutic benefits can be derived (Linsteadt, 2002, p. 20).

Similarly, one cannot understand the impact of body disfigurement in isolation from the rest of each person's experiential world. Healing takes many forms and exists at many levels, with each experience unique to the individual. Becoming aware of how some individuals describe their non-acceptance of the embodied self in terms of their concept of self in their relation to the world, might provide a space for medical and mental health professionals alike to help foster more positive and accepting body narratives (Van Deurzen-Smith, 1997, p. 108).

As a final note, the aim of this article was to alert researchers to the need for qualitative, and, in particular, phenomenological research in the area of body disfigurement and self-concept so as to help map the territory with regard to the lived experience of people afflicted with disfiguring dermatological conditions. Research of this kind has important implications for all health care professionals in helping to effect positive change in the therapeutic domain.

### About the Author

Tracy Watson was born in Essex in the United Kingdom and immigrated to South Africa in 1981. After spending more than a decade in the banking and public relations sector, she spent three months in Surrey, United Kingdom, working as a nursing auxiliary. On her return to South Africa, Tracy worked for two years in Industrial Relations before enrolling at the University of the Witwatersrand, where she obtained a BA in Psychology and Sociology, and, in 1999, an Applied Honours Degree in Psychology, qualifying as a psychometrist the following year after completing her training at the Johannesburg General Hospital Psychiatric Unit. After studying alternative therapies for two years and qualifying in Therapeutic Reflexology and Reiki Healing, Tracy was admitted into the MA/DLitt et Phil (Psych) doctoral training programme at the University of Johannesburg. Having completed her Master's degree in Psychology, graduating Cum Laude, she is currently completing her internship for the doctoral degree in clinical psychology at Tara Hospital. Tracy has a holistic integrative approach to psychological research and believes that both quantitative and qualitative methods of investigation are fundamental in researching complex phenomena in psychology. This is her first publication.



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