Psychosocial impact of dermatology diseases

Doctor of Medicine – MD
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Order

1. Title Page
2. Dedication
3. Acknowledgement
4. Publication out of this MD
5. Table of Contents, with page references
6. List of Tables, with page references
7. List of Figures with page references
8. Chapters 1 to 7
9. Bibliography
# Table of contents

Declaration. ........................................... 1  
Acknowledgements. ................................. 2  
Publications out of this MD. ...................... 3  
MD outline ........................................... 5  

**Chapter 1**  
Introduction of thesis ............................. 6  
Skin diseases and Quality of life ................. 9  

**Chapter 2**  
Review of the literature .......................... 13  
  Quality of life in Dermatology .................. 14  
  Psychological impact of skin disease .......... 17  
  Social impact of skin diseases ................. 20  
  Pathogenesis of skin diseases and stress ...... 22  
  Review of literature on atopic dermatitis and quality of life 26  
  Psychological impact on families .............. 28  
  Review of literature on patients‘ fears, expectation  
and satisfaction .................................. 32  
  Review of literature on delusion of parasitosis 36  

**Chapter 3**  
Measuring the severity and impact on quality of  
life of infants with atopic dermatitis ............ 41  
  Introduction. .................................... 42  
  Aim ............................................. 48  
  Methods. ....................................... 49
<table>
<thead>
<tr>
<th>Quality of questionnaires.</th>
<th>51</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disease severity questionnaires.</td>
<td>53</td>
</tr>
<tr>
<td>Statistical analysis.</td>
<td>55</td>
</tr>
<tr>
<td>Results</td>
<td>56</td>
</tr>
<tr>
<td>Quality of life.</td>
<td>56</td>
</tr>
<tr>
<td>Severity scores.</td>
<td>58</td>
</tr>
<tr>
<td>Discussion.</td>
<td>60</td>
</tr>
<tr>
<td>Role of nursing in management of AD</td>
<td>63</td>
</tr>
<tr>
<td>Conclusions.</td>
<td>66</td>
</tr>
</tbody>
</table>

### Chapter 4
**Patient Fears, Expectations and Level of understanding: the hidden agenda in the dermatologic consultation**

| Introduction | 84 |
| Methods | 87 |
| Results | 89 |
| Patients fears | 89 |
| Patient's expectations | 90 |
| Post consultation satisfaction | 91 |
| Discussion. | 92 |
| Limitations of study. | 95 |
| Strengths of study. | 95 |
| Conclusions. | 96 |

### Chapter 5
**Poor prognosis in delusion of parasitosis - lessons learnt**

| Introduction | 102 |
| Aim | 110 |
| Methods | 111 |
| Results | 112 |
| Antipsychotic treatment | 114 |
| Discussion | 116 |
| Do's and Don'ts. | 122 |
| Limitations of study. | 124 |
| Patient's point of view | 124 |
Chapter 6
Exploring the role of the clinical psychologist in Dermatology clinic

Introduction 135
Methods 140
Questionnaires 141
Results 144
Case histories 145
Discussion 160
Feedback from the consultation with clinical psychologist 165
Conclusions 166

Chapter 7
Conclusions of the thesis 172

Bibliography 177
List of Tables

Table 2.1 ................................................................. 25
Table 3.1 ................................................................. 67
Table 3.2 ................................................................. 68
Table 3.3 ................................................................. 69
Table 3.4 ................................................................. 70
Table 3.5 ................................................................. 71
Table 3.6 ................................................................. 72
Table 3.7 ................................................................. 73
Table 3.8 ................................................................. 73
Table 3.9 ................................................................. 74
Table 4.1 ................................................................. 97
Table 4.2 ................................................................. 98
Table 4.3 ................................................................. 98
Table 4.4 ................................................................. 99
Table 5.1 ................................................................. 129
Table 5.2 ................................................................. 131
Table 6.1 ................................................................. 169
Table 6.2 ................................................................. 170
Table 6.3 ................................................................. 171
List of figures

Figure 3.1. ......................................................... 75
Figure 3.2. ......................................................... 76
Figure 3.3. ......................................................... 77
Figure 3.4. ......................................................... 78
Figure 3.5. ......................................................... 78
Figure 3.6. ......................................................... 79
Figure 3.7. ......................................................... 80
Figure 3.8. ......................................................... 80
Figure 3.9. ......................................................... 81
Figure 3.10. ....................................................... 81
Figure 3.11. ....................................................... 82
Figure 3.12. ....................................................... 82
Figure 3.13. ....................................................... 83
Figure 3.14. ....................................................... 84
Figure 3.15. ....................................................... 84
Figure 5.1. ......................................................... 131
Figure 5.2. ......................................................... 131
Figure 5.3. ......................................................... 133
Dedication

To my parents, my wife and my three beautiful kids Araiz, Ayla and Arbaaz
Declaration

I declare that this thesis has been composed by me and that the work herein is my own and has not been submitted in candidature for any other degree, postgraduate diploma or professional qualification.
Acknowledgements

Many people have given help in various ways during the course of this thesis. Firstly and mostly I would like to thank my supervisor, Dr Bart Ramsay, for the time that he has given to me over last three years. Without his support and advice this thesis would have been a much more difficult undertaking and he has shown a constant understanding of the direction where I wanted to go in my research. I will be forever grateful for his insight and knowledge.

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A major thanks to my wife who has given me a great support throughout my work and was very patient during difficult times. Lastly, I give my love and thanks to my parents. I do not think I could ever have reached the place I am now.
Publications out of this MD

Original Papers


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68th American Academy of Dermatology Annual Conference (San Francisco 2009)

88th Annual Meeting of the British Association of Dermatologists, Liverpool, UK, July 2008


87th Annual Meeting of the British Association of Dermatologists, Birmingham, UK, July 2007

MD outline

Chapter 1
Introduction of thesis

Chapter 2
Review of literature

Chapter 3
Quality-of-Life Measure for Young Children with Atopic Dermatitis and their Families

Chapter 4
Patient Fears, Expectations and Level of understanding: the hidden agenda in our consultations

Chapter 5
Poor prognosis in delusion of parasitosis - lessons learnt

Chapter 6
Exploring the role of the clinical psychologist in Dermatology clinic

Chapter 7
Conclusion of the thesis
CHAPTER 1

Introduction of thesis
Introduction of thesis

Working in dermatology, one quickly learns that applying a simple medical model approach of diagnosis and treatment is neither suitable nor sufficient. In some patients the dermatological disease makes the patient suffer so much that psychological support is clearly needed and for others their skin condition does not respond to appropriate treatment so the patient requires ongoing support for their condition. Furthermore, some patients have primary psychiatric disorders - such as delusional parasitosis (DP) - but do not want or will not consult psychiatrists (Lyell 1983). These patients thus need psychologically adapted care in dermatology.

During my training in Dermatology, I have developed a special interest in studying the impact on quality of life of chronic dermatoses like atopic eczema and psoriasis.

So, this thesis focuses on the effects of atopic dermatitis on quality of life and on patients' knowledge, expectations and fears about their skin conditions. I also have included DP, a psychiatric illness that has significant morbidity but which presents to dermatologists and poses unique difficulties. Finally as part of evaluating how we should respond to the psychological challenges seen in our patients, I studied the use of an assessment and counselling service provided by a clinical psychologist in the dermatological outpatient setting.
This thesis focuses on the psychological impact of skin disease on the sufferer and looks at ways to measure this impact. By attempting to measure quality of life, we can ascertain the effects of disease upon individuals from the patient's / child's / parent's perspective and thereafter, to some extent, be better able to judge the benefit of therapeutic interventions.

The thesis is based exclusively on patients from Mid-Western Region, Ireland. These are all patients referred to the Dermatology Department at Mid-Western Regional Hospital, Limerick by their family practitioners.

The thesis is divided into 7 chapters.

In Chapter 2, I review the existing literature covering impact of skin diseases on patients.
In the 3rd chapter I study the effect on QoL in atopic dermatitis children and their families.
In the 4th chapter I describe the use of a novel clinical tool to elicit patient fears or concerns, about their skin condition and their expectations of treatment.
The 5th chapter studies an example of a psychiatric condition – delusional parasitosis - that largely presents to dermatologists.
The 6th chapter looks at the emerging role of the liaison clinical psychologist within the dermatology clinic.
The 7th chapter contains the conclusions of the thesis and overview of the work presented.
Skin diseases and Quality of life

Skin diseases are frequently more visibly obvious than other chronic diseases such as asthma or diabetes and more likely to lead to alienation, name calling, teasing and bullying (Beatie PE et al 2006)

Until recently, the focus of many studies in dermatology was on quantification of the disease extent or physical symptoms. More latterly it has been appreciated that documenting disease impact is critical, firstly to acknowledge the hidden impact on the patient and secondly, to help improve patient compliance or concordance with treatment i.e. listening to where the patient is at with their particular problem improves the consultation process and allows a collaborative joint approach between patient and doctor in the treatment plan (Picardi A et al 2000, Lewis-Jones MS et al 1995).

Quality of life (QoL) is a multidimensional concept that is difficult to define and measure. The definition of QoL is different for everyone but at its essence is a life of meaning and purpose. The main thing that determines QoL is the ability to enjoy all that life has to offer and make choices about what a person wants to do with their time.

QoL can be defined as 'the difference, or the gap, at a particular time between the hopes and expectations of the individual and that individual's present experiences' (Calman et al 1984).
Gill's and Feinstein's define QoL as the way patients sense and react to their health conditions and to non-medical aspects of their lives (Gill et al 1994). According to this viewpoint, one's QoL comprises factors such as physical, functional, emotional, and intellectual well-being, work, family, friends, and other particulars.

WHO defines QoL as "individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns." (Study protocol WHO 1993)

It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment.

Health-related QoL (HRQoL), is a more limited concept used to describe the effects that a disease or its symptoms have on an individual's life (Koo et al 2003). HRQoL is the subjective perception of the impact of health status, including disease and treatment, on physical, psychological and social functioning and wellbeing (Detmar et al 2002). Measuring QoL has particular significance for dermatological conditions as, although many are not generally life threatening, they frequently have a major impact on patients' psychosocial state, social relationships and everyday activities (Guyatt et al 2007).
Attempts to develop methodology to measure the adverse impact of skin disease on quality of life started in the 1980s and within two decades have become firmly established (Finlay et al 1987, VanBeek et al 2007).

HRQoL is generally measured with reliable and valid self-reported instruments (ie, questionnaires). The application of such questionnaires in daily clinical practice may improve evidence-based practice, facilitate communication with the patient, and, herewith, the process of shared decision making between patients and physicians (Prinsen et al 2010).

As a result, many different instruments for measuring severity and QoL have been developed specifically for patients with dermatological diseases, aimed at both the adult and paediatric populations (Lewis-Jones et al 1995, Finlay et al 1994).

A lot of dermatologic research has focused on measuring physical disease extent. Skin diseases in addition to their visible effect and symptoms also have a profound impact on quality of life for the patient. Only relatively recently has there been increased research and measurements made on disease impact (Valderas JM et al 2008). The impact of skin disease on patients' lives are often overlooked by physicians, the general public and health policy makers (Finlay et al 1995, Finlay 1987). Because chronic skin diseases are often not life threatening, attention and funds may be diverted to diseases that are perceived as more serious.
Furthermore, with finite health service funding, it is important to document disease severity not only from the physical aspect but also quantifying the psychological and social impact as this makes it possible to justify the cost of treatment programmes (Jayaprakasam et al 2002).
CHAPTER 2

Review of the literature
Quality of life in Dermatology

As an easily noticed and touched organ, skin plays an important role in the socialisation process, which continues from childhood to adulthood. Ingram stated that the skin is an extension of the mind and, therefore, is an essential part of character and personality assessment (Ingram et al 1933).

In recent past, research and subsequent evidence based medicine has led to the advent of a patient-orientated view of dermatology (Finlay et al 1994). A large body of published research now indicates that many skin diseases and conditions have a negative psychological impact on patients and on their families, and can lead to long-term problems in many aspects of life (Schmitt et al 2007, Beattie et al 2006).

Skin diseases adversely affect multiple domains of the quality of life (QoL), including emotional, social, and economic aspects (Rapp et al 2001). Because most research on skin-related QoL has been conducted on clinical samples, there is little evidence available on how skin ailments affect QoL in the general, nonclinical population. In addition, it is difficult to ascertain whether skin-related QoL, a subjective evaluation, is more closely linked to a person's reported skin ailments and symptoms or to a dermatologist's diagnosis of that person's skin diseases (Feldman et al 1997).
Chronic skin diseases have been recognized as having a detrimental effect on patients’ QoL, also causing considerable mental discomfort. Reduced self-acceptance, low self-esteem, a negative body image, and a low sense of self-worth have been noted in patients with visible skin disorders (Butters et al 1987). Sadly, some patients even develop suicidal ideation (Gupta 2010, Rapp et al 1999).

Cotterill and Cunliffe reported 16 patients who committed suicide after presenting with dermatological problems. Most of the patients had either a body image disorder (dysmorphophobia) or acne. Patients with long-standing and debilitating skin disease may become depressed enough to commit suicide and it is important to recognize these patients with the risk of suicide (Coterill et al 1997).

QoL measures are particularly important in skin disease where there may be no cure. Conditions such as atopic dermatitis (AD) and psoriasis, although not life-threatening, may be chronic. It is important to assess patient morbidity from the patient’s perspective rather than the doctor’s perspective. There are multiple health related QoL tools which measure the effect of skin disease on QoL and a range of important studies quantifying the impact of many skin diseases on the QoL of patients and, more recently, their families (De Korte et al 2002, Frisén 2007, Basra et al 2007).
Many skin diseases have been demonstrated to result in significant stress and impairment of quality of life for patients. This may be related to a number of factors and is not necessarily related to disease severity (Jayaprakasam et al 2002). Cosmetic disfigurement and social stigma are important in skin diseases (Ramsay et al 1988, Ginsburg et al 1989).

Unpleasant symptoms, such as itching and pain, are important in AD (Finlay 1996). Other factors affecting quality of life include impact on social activities and interactions with friends and family, financial burdens, impact on work and psychological factors (Lewis-Jones 2005).

Traditionally, outcomes in medicine and health care have largely been determined by the objective medical evaluation (e.g., measurable changes in health parameters, disease status, cost of care). Increasingly, it has become clear that the perspective of the patient is a critical variable. As a result, emphasis has shifted gradually toward including evaluations of medical / health-related outcomes from the patient’s perspective (Testa et al 1996).

Such assessments potentially are of use to clinicians, researchers, administrators, and policy makers since they offer a profile of the current state of an individual who is experiencing a particular chronic disease. They provide additional information beyond that offered by traditional medical and clinical
measures and thus are valuable in helping to understand the wide variability in individual responses to similar disease.

Psychological impact of skin disease
Psychological factors have long been associated with the onset and exacerbation of many cutaneous diseases (Engles et al 1982). Cutaneous diseases are unique in that, unlike many other illnesses, they are often visible to others and consequently social factors in coping and adjustment are highly relevant.

The link between dermatological and psychological conditions has become more prominent in the published literature over the two decades (Finlay et al 1995, Al' Abadie et al 1994; Elden et al. 1994; Papadopoulos et al 1999).

Skin diseases are frequently accompanied by significant changes in physical appearance. The visibility or prominence of the disease may attract attention in social situations, thus hindering the patient from keeping their condition a private or personal matter (Krejci-Manwaring et al 2006). The physical changes from the skin diseases can have a negative effect on body image (Butters et al 1987).

It is well-documented fact that skin diseases are sometimes associated as contagious or because of lack of hygiene (Kleinman et al 1988). The sufferer
may find that others react negatively towards them, or treat them differently because of the appearance.

Cutaneous conditions can often be progressive making it necessary for the patient to have to psychologically continually adapt to changes in their physical appearance, unlike disfigurement resulting from illness or trauma (Ramussen et al 1990).

The American writer John Updike who himself suffered from psoriasis, once described that he could not pass by a reflective surface like a mirror or glass without pausing to check and see if his skin condition had by chance cleared up (Updike 1985).

The patient may begin to feel socially handicapped and start to avoid certain situations. People who suffer with dermatological conditions have been found to experience higher levels of distress than the general population (Root et al 1994). As a result, these patients start to avoid social activities, especially those such as swimming where the skin might be exposed and to have lower body image and self-esteem than the general population (Gupta et al 2010, Rubinow et al 1987).

Golics et al in their study reported the psychological impact of skin disease on adolescents expressed by the majority of patients. Bullying and being judged by others because of their skin had a major impact on many of the patients and
led to the negative emotions described. As a result of bullying and negative comments, self-esteem was also affected in a number of patients (Golic et al 2009).

The effect on swimming was an important issue in the study. The main reasons given for swimming being affected were feelings of self-consciousness about exposing skin and of worrying about other people's reactions (Golic et al 2009).

The links between psychological health and the onset and course of many cutaneous conditions are still not well established. Psychological factors have been linked to dermatological illness in various ways. There is evidence to suggest a higher prevalence of psychiatric disorder in dermatology patients than in either the general population or a general medical inpatient population (Evers et al 2008, Hughes et al. 1983).

A depressive illness is a disabling, overpowering experience affecting thinking and the way a person feels, disturbing sleep, appetite, and energy. At some level, the person feels unable to cope. It is useful to distinguish it from normal depression, that is, the ups and downs of everyday life (Bodkin et al 1995). Reactive depression is purely an understandable reaction to a significant loss and the symptoms are of anxiousness, sadness, tension, irritability, feeling worse in the evenings, and having trouble getting to sleep at night (Bodkin et al 1995).
Depression affects a sizeable proportion of patients with dermatological problems. 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 et al. 1980).

Although the pathophysiological mechanisms through which skin diseases (psoriasis and alopecia areata) act are different, they share an important feature in that they are visible to others. 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 et al 1992).

Social impact of skin diseases
Skin diseases are often considered dirty, ugly or even contagious both by non-affected people and by those suffering from the condition (Kleinman et al 1988). This has implications for both personal and intimate relationships. The social and emotional impact of a skin condition can be considerable. The feeling of being stigmatized or being different from others is a common reaction and may affect a person's interpersonal and social behaviour (Lansdown et al 1997).

People with visible skin conditions tend to be perceived as different from those whose appearance is unremarkable. Indeed, due to the social significance of the skin (Nadelson et al 1990), 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 et al 1990).

The 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. It may be further influenced by the demands placed on individuals by their social and cultural environment. Subjective evaluations of how well a person's appearance conforms to these demands can significantly affect self-esteem and body image (Butters et al 1987). Therefore the skin condition may not have to be severe for the individual to negatively evaluate their ability to conform to social standards. Altered body image is a potential and actual source of considerable distress, particularly following facial disfigurement, and social functioning is reported as a major area of difficulty by sufferers. The area of facial disfigurement has received comparatively little attention from researchers in health care. It is suggested that the avoidance present following disfigurement is phobic in nature, and special attention is given to the roles of avoidance and confrontation in mediating these difficulties (Newell 1999).

A visible skin disease can adversely affect body image, confidence and, in certain instances, a person's overall QoL. The size and location of skin problem may also have an impact on the extent to which the disfigurement will affect the patient's life (Beattie et al 2006, Basra e al 2007).
Pathogenesis of skin diseases and stress

Several different approaches have been used to understand the aetiology of psychogenic skin disease. The multifaceted interaction between psychology and dermatology provides the rationale for the establishment of societies of psychodermatology, whose research in both fields underscores the variety and extent of connections between the two.

The effect of stress on the immune system and the skin

The mechanisms relating psychological stress, personality and emotion to atopic diseases also continue to be investigated. Hormones and neuropeptides released into the circulation when individuals experience stress are thought to be involved in regulating both immune-mediated and neurogenic inflammatory processes (Wright and Cohen et al 2005).

Dysregulation of normal endocrine and immunologic mechanisms can occur in the face of chronic stress, leading to chronic hyperarousal or hypo-responsiveness that may affect disease expression. These responses may in turn have an influence on mood and well-being. Therefore, it is also important to clarify to what degree atopic diseases affect psychological state (Wright 2005, Marshall et al 2007).

One study, which examined the psychosomatic aspects of skin disease in relation to immunology, found that emotional stress had the capacity to influence the immune system to a great extent, and this would often manifest in
cutaneous illness (Teshima et al. 1982). They found that tension in patients could lead to an enhancement of allergic reactions, and that allergic patients improved with autogenic training and relaxation.

**Review of literature on atopic dermatitis and quality of life**

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 ignored by dermatologists, particularly if the skin problem is not regarded as serious or life threatening (MacGregor et al 1990, Schiffner et al 2003).

Jowett and Ryan interviewed 100 people with acne, psoriasis and eczema who attended a hospital outpatient clinic (Jowett et al 1985). They found that patients’ lives had been affected in numerous ways by their skin condition, including difficulties in their self-esteem and relationships, reduced opportunities in finding employment, functional and interpersonal problems in the workplace, increased levels of anxiety, lack of confidence and depression.

Eighty per cent of patients indicated that they were embarrassed and self-conscious about their appearance and felt that people were likely to stare at them (Jowett et al 1985).
For a long time the impact of disease on patients was measured simply in terms of mortality indexes. It was within this context that the concepts of quality of life and health-related quality of life emerged (Frisén 2007).

Over the last decade, these measures are used in healthcare and are considered indispensable for approving and defining treatments and for assessing the cost-benefit relationship of care provided.

Worldwide interest in the subject has led to the development of many instruments; some generic intended to assess the quality of life of populations in general and others specific designed for groups of individuals suffering from a specific acute or chronic disease (Grange et al 2007). In general, chronic diseases are the primary focus of quality of life assessments, since they have a major impact on patients’ lives (Klatchoian et al 2008).

Over next few pages, I have discussed and reviewed the literature on atopic dermatitis and its effect on quality life Table 2.1
<table>
<thead>
<tr>
<th>Disease severity measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rajka Langland Severity Classification (Rajka G et al 1999)</td>
</tr>
<tr>
<td>SCORAD (European task force 1993)</td>
</tr>
<tr>
<td>Eczema Area and Severity Index (EASI) (Hanifin et al 2001)</td>
</tr>
<tr>
<td>Patient Orientated Eczema Measure (POEM) (Charman et al 2004).</td>
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<tr>
<td>Three-Item Severity Score (TIS) (Wolkerstorf er et al 1999)</td>
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</tbody>
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<th>Dermatology-specific c measures</th>
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<tr>
<td>DLQI (Finlay A 1992)</td>
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<tr>
<td>CDQLI (Lewis-Jones MS et al 1995)</td>
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<td>IDQOL (Lewis-Jones MS et al 1999)</td>
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<th>Family impact measures</th>
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<td>Dermatitis Family Index (DFI) (Lawson et al 1998),</td>
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Atopic dermatitis and quality of life

Atopic dermatitis (AD) is a chronic disease characterized by intense itching, dry skin, inflammation, exudation, and there are skin relapses and remissions, generally induced by environmental stimuli.

The diagnosis of AD is based on the clinical findings of pruritus, facial and flexures involvement in infants and children and chronicity of the dermatitis (Hanifin 2001, Williams et al 1994). The cause of atopy is probably multifactorial, with influences from both genetic and environmental factors, although the rapid increase in prevalence in the past decades suggests environmental precipitants (Hoffjan et al 2005, Morar et al 2006, Sugiura et al 2005, Flohr et al 2005).

Quality of life is a major concern in AD. It has been recognized that chronic childhood illness has the potential to induce stress on the affected child as well as on the family (Basra et al 2007).

The dynamics of QoL include much more than the status of an individual's health and furthermore, it is the interaction of all potential influences that determine life quality (Parmenter et al 1994).

AD has as larger impact on HRQoL as several chronic conditions and other dermatologic conditions. Kiebert et al in his study aimed to determine the
HRQoL of patients with AD by disease severity and to compare it with that of the general public and of patients suffering from other chronic illnesses or skin disorders (Kiebert et al 2002). They concluded that AD has an impact on HRQoL, particularly in social functioning and psychological wellbeing. Patient-assessed severity of atopic dermatitis correlates with HRQoL decrements, indicating greater HRQoL impact with greater disease severity.

There are wide variations in how people cope and adapt from the impact of skin diseases on their QoL. Patients may experience feelings of shock, denial, anger and sadness, before accepting the change. They may need support of friends and family to help them cope with the challenges of skin disease while others may require the intervention of professionals (Lawson et al 1997).

Ben-Gashir et al reported the impact of AD on children’s QOL and its relationship to disease severity. The study provided the evidence on children’s QOL scores significantly correlated to their AD severity as assessed by the observer and changes in children’s QOL scores were significantly related to changes in AD severity scores (Ben-Gashir et al 2004).

In a German study comparing infants with AD to normal infants, mothers of infants with AD showed more anxious and overprotective attitudes when surveyed (Pauli-Pott et al 1999). In addition, the burden of caring for the child
with AD can negatively affect spousal relationships and interfere with giving adequate attention to siblings (Daud et al 1993, Lapidus et al 1993).

The psychological impact of AD on children and their families are well documented (Lewis-Jones 2006, Absolon et al 1997, Su et al 1997), with sleeplessness and its consequences leading to impaired psycho-social functioning of the child and the family.

If a negative relationship between primary caregiver and child is not resolved, then the implications for emotional and social development will not only have an effect on psychosocial development during childhood but may continue into adolescence (Basra et al 2007).

**Psychological impact on families**

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 (Su et al 1997). The diagnosis of a chronic 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 (Lawson et al 1997).

Chronic skin diseases such as atopic dermatitis can directly affect family members as parents may blame themselves if they believe the disease to be
hereditary and siblings may fear acquiring the disease themselves (Basra et al 2007).

The relationship between the child and the parent may have implications on how the child copes with the illness. One significant etiologic factor in the development of behavioural problems of children with illness is the reaction of the parents to the illness of the child. Overprotective parents may prevent the development of peer relationships and social skills, which are vital for later developmental tasks (Lewis-Jones 2005).

Why some people adjust well to the challenges of skin disease while others do not is not well understood. However, there is evidence to suggest that equipping people with efficacious problem-focused and emotion-focused coping tools can positively affect their ability to deal with their condition, such as self-esteem and body image (Papadopoulos et al. 1999).

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. It is important, therefore, that dermatologists and psychologists work more closely in helping to address the needs of these patients and their families.
The important points on reviewing the literature of AD are summarised as follows:

- Inflammatory skin diseases such as psoriasis and atopic dermatitis have a greater impact on QoL than hypertension and angina (Finlay 1990) and have as much negative physical, social and psychological impact as life-threatening conditions such as angina or cancer (Rapp et al 1999).

- Willingness to pay studies show that the willingness to pay for a cure was greater for acne, AD and psoriasis than angina, hypertension and asthma (Parks et al 2003).

- More recent studies have identified the significant impairment that skin disease can have on the partners and relatives of those affected (Eghlileb et al 2007, Basra 2007).

- There is evidence that life choices and employment opportunities are influenced by chronic skin disease (Bhatti et al 2009).

- The use of QoL assessment in the consultation can influence management decisions and, when used in combination with the clinical assessment of disease severity, has the potential to influence management decisions (Katugampola et al 2005, Salek et al 2007).

- Psychiatric and psychological factors have been documented as playing an important role in a quarter of patients presenting to a dermatology outpatient clinic (Picardi et al 2000).
• A clear link had been described between psychological morbidity and psoriasis, AD in childhood, and acne (Gupta et al 2003, Griffiths et al 2001, Lewis-Jones 2006, Yazici et al 2004).

• The clinical severity of the disorder as assessed by the physician is a less good predictor of the psychiatric morbidity than a measure of the impact of the condition on the patient’s QoL in many cases (Picardi et al 2000, Gupta et al 2003).

Studies in this area make clear recommendations that clinicians should supplement clinical assessment of disease with formal evaluation of impact on QoL using the validated tools available (Sampogna et al 2003).

Health planners need to be mindful of this evidence of the impact of skin diseases on QoL and psychosocial factors when allocating resources. Measures of QoL have particular significance for dermatological conditions as, although not generally life-threatening, they frequently have a major impact on patients’ psychosocial state, social relationships and everyday activities and their families. Longitudinal studies would allow for the examination of the interaction between psychological variables and skin disease across time. The majority of studies have tended to be quantitative in design and much of the depth of information regarding a patient’s beliefs about skin disease is invariably lost.
Review of literature on patients’ fears, expectation and satisfaction

Studies on patients’ fears, their concerns and expectations from the physician are very limited. In the fourth chapter, a novel tool that can be used in the clinical setting to enable the consultation to focus on patients’ current concerns for their skin as well as their therapeutic expectations is described.

Patients’ needs and expectations are extremely complex and contextual: Patient satisfaction with health service delivery organization is influenced by how the patient subsequently evaluates the experience. It is also linked to the patient's overall life satisfaction, another subjective determination (Dieneret al. 1999).

Patient satisfaction is regarded as an attitudinal response to value judgments that patients make about their clinical encounter including an assessment of its quality (Waitzkin 1991). People may come to dermatologists with high expectations of a definitive cure for all their skin disorders. Experience tells us that it is not possible for us to guarantee such solutions. This leads to a huge gap between the service provider and the service seeker, leading to decreased patient satisfaction (Poulas et al 2008).

Poor communication with physicians, lack of empathy, and the chronicity of many of the disorders lead to dissatisfaction. dermatologist's professional job satisfaction and a patient's satisfaction need not necessarily complement each
other (Renzi et al 2001). We rate our job satisfaction by our professional knowledge, attending CMEs, conferences, mastering new skills, and keeping pace with new technologies. All these factors are not always relevant to the patient. Ultimately however, whether a patient is happy with a doctor's approach depends on different nonclinical factors like listening to him or her, promptness of services, and how we talk and gesture (Luecke et al 1991, Foot 2004).

Expectation is an important element of patients' ratings because an evaluation of a health care provider's behaviour is based on one's expectations for treatment-unmet expectations will lead to dissatisfaction and met expectations to satisfaction, which can be defined as the fulfilment of both wants and predictions (Marpleet al. 1997). They define background expectations as those based on the experiences of the patient in a clinical setting. Background expectations vary according to the particular illness and circumstances, but certain patterns of activity or routines are expected. To some degree, background expectations are shaped by past experiences, including routine behaviour, history of visiting doctors, contacts with physicians in daily life, prior satisfaction with providers, and other people's experience (Jackson et al 2001).

Patient satisfaction is an increasingly important objective for health services (Scott et al 1994, Epstein et al 1990). This trend reflects the reality that the choice and success of many treatments are based on subjective patient-

However, expected improvement, actual outcome, and expectation-outcome discrepancy were all moderately correlated with satisfaction. Clearly, patient satisfaction is a complex and multidimensional construct that cannot be explained by a single variable (Williams et al 1994). It is worth noting that neither actual improvement nor actual outcomes are predictive of patient satisfaction but it is the expectation-outcome which is the most important factor.

Previous study to formally document patient expectations, demonstrated that patient expectations are unreasonably high and few patients realistically achieve them (Tielsch et al 1995).

To provide the highest level of satisfaction, health care professionals must control their patients' expectations and understanding of treatment and the close relationship between accurate patient expectations and adequate informed consent cannot be ignored (Yucelt et al 1994). In fact, to improve patient satisfaction, health care professionals would be advised to pay more attention to patient understanding and expectations, even at the expense of improving patient outcome.
Patient satisfaction surveys often report remarkably high levels of contentment or satisfaction with health services. For some components of care this may indeed be a valid reflection of patient views and not simply an artefact of survey design and conduct. However, it has long been acknowledged that the wording and presentation of questions may influence responses.

We have proposed using a novel tool to identify the impact of skin disease from patient's perspective focusing on their fears and level of understanding of their skin condition as well as their expectations and satisfaction following the consultation.

We have highlighted in chapter 4, the particular points where greater attention need to be made to understand patients' fears and level of understanding as well as patients' expectations.
**Review of literature on Delusion of parasitosis**

Research into the more severe manifestations of psychocutaneous disorders, such as delusions of parasitosis and dermatitis artefacta have led to an increasing awareness of other psychosocial effects of skin diseases. These effects include a decreased sense of body image and self-esteem, sexual and relationship difficulties, a generalised sense of reduced QoL and depression (Dungey et al 1982; Porter et al. 1990).

Following the original description of Koblenzer, psycho-cutaneous diseases (Koblenzer 2010) can be classified based on their primary etiology as:

**Psychiatric disorders without significant dermatological disease**

- Delusional syndromes, Parasitosis, Smell, Impregnation and contamination, *Folie à deux*
- Other hypochondrias, e.g. so-called Morgellons
- Disorders of awareness of the body Phobias and obsessive compulsive disorders
- Disorders of body image: body dysmorphic disorder (BDD) (synonyms dysmorphophobia, dermatological non disease)
- Disturbance of body size and eating, e.g. anorexia nervosa, bulimia
- Phobias, e.g. mole phobia, venereophobia, wart phobia, erythrophobia, electrophobia and steroid phobia
- Obsessive–compulsive behaviours, e.g. hand washing, hair plucking
- Atypical pain disorders, e.g. glossodynia, vulvodynia and scrotodynia, anodynia
- Pruritis sine materia
- Other dermatologic hypochondrias: botoxophilia, tanorexia, cyberchondria
Dermatoses primarily factitious in origin

- Dermatitis factitia
- Artefact by proxy
- Witchcraft syndrome
- Malingering
- Münchausen's syndrome
- Fabricated and induced illness (Münchausen's syndrome by proxy)
- Deliberate self-cutting
- Self-mutilation

Difference between psychotic disease states and psychological disturbances

(DSM iv 1994)

Psychosis, or a psychotic disorder, refers to any mental state that impairs thought, perception, and judgement. Psychotic episodes might affect a person with or without a mental disease. A person experiencing a psychotic episode might hallucinate, become paranoid, or experience a change in personality.

A psychological disorder, also known as a mental disorder, is a pattern of behavioural or psychological symptoms that impact multiple life areas and/or create distress for the person experiencing these symptoms (American Psychiatric Association DSM iv (1994)).

Witchcraft's syndrome, originally described by Meadow, is a form of child abuse meeting four criteria (Krener 1994):
1 Medical illness is fabricated in a child by a parent (usually the mother), the perpetrator.

2 The child is brought for medical evaluation or treatment.

3 The perpetrator denies his or her actions.

4 The "illness" disappears when the child and perpetrator are separated.

**Delusional parasitosis**

Delusional parasitosis (DP) is a rare psychiatric disorder in which the patient has a fixed, false belief that he or she is infested by parasites. Even though it is a psychiatric disorder, these patients usually present to a dermatologist because they are convinced that they have a dermatologic problem. Patients with delusions of parasitosis generally reject psychiatric referral (Lyell et al 1983).

The chief complaints of patients with DP are (i) the rigid belief against all medical evidence that they are infested and (ii) abnormal sensations —as if infectious agents evoke them (e.g., using description such as —crawling," —biting," —leaving marks," and —building nests"). Thus, two complementary symptoms define DP.

Common and classical cutaneous symptoms of crawling, biting, and stinging sensations are the first evidence of delusion. They will usually have tried various measures for eradicating the organism, such as using pesticides on themselves, repeatedly hiring pest-control services, and even consulting
entomologists to identify the parasites. They may have changed residence several times in an attempt to escape the parasites and may socially isolate themselves because of fear of passing it to others (Bewley et al 2010).

Berrios et al reported the possible interplay between a tactile hallucination and then subsequent delusion (Berios et al 1982). Berrios speculates that patients perceiving tactile sensations switch from considering the sensations —as if” insects were crawling on the skin to definitely crawling on the skin.

Lyell surveyed 374 British dermatologists about their findings in psychogenic parasitosis; 193 Dermatologists reported their observations of 282 total patients (Lyell 1983). Lyell reported that females experienced the disorder twice as often as males across the life span, except prior to age 50, when female-to-male incidence was identical. Lyell’s survey indicated that it was rare for the disorder to begin with a genuine parasitic infestation, present in only about 2% of cases.

Trabert estimated that the incidence of DP in Germany was 1.6 cases per million people (Trabert 1995). In the same study of 1223 case reports, the mean duration of symptoms was 3.0 +/- 4.6 years. In common with previous reports of DP, our patients had chronic symptoms with a mean duration of 44 months. Because of this, such patients may have already been evaluated by many different physicians.
The management of DP is not straightforward. Slaughter et al proposed a stepwise approach for Dermatologists, with recommendations for the first and later visits (Slaughter et al 1998).

DP is a disabling psychiatric disorder seen primarily by dermatologists and primary care physicians. The psychiatric literature contains detailed recommendations about dealing with these patients in psychotherapy (Torch et al 1981) but most dermatologists and many primary care physicians have neither the training nor the time for real psychotherapy or for making a precise psychiatric diagnosis. Even with best efforts, many patients leave medical care without being helped. Success with a combined dermatology–psychiatry clinic has been described and may be ideal for patients with psycho-cutaneous disease (Aw et al 2004)
CHAPTER 3

Measuring the severity and impact on quality of life of infants with atopic dermatitis
Introduction

Atopic dermatitis (AD, synonymous with atopic eczema) is particularly common in young children under five years of age. It has significant morbidity and imposes a high economic burden (Williams 2005, Leung et al 2003, Carroll et al 2005). It is therefore at its most prevalent and troublesome at an important time in the child’s emotional and social development. It accounts for 10-20% of referrals to secondary care dermatology clinics and occupies much valuable time and resources (Ring et al 2004).

Adequate laboratory tests to assess disease severity in randomized controlled trials (RCTs) and to monitor treatment in clinical practice do not exist (Chren 2005). Therefore valid and reliable clinical outcome measures are a necessary prerequisite for good evidence-based practice and there is now a website for RCTs in AD Global Resource of EczemA Trials (GREAT database) 2000 – 2011 (www.greatdatabase.org.uk).

Atopic eczema is characterised by itching and ill-defined areas of redness and scaling typically affecting the limb flexures. The face may also be affected, particularly in infants and adults, but eczema may affect any part of the skin surface. In the acute stage, vesiculation, weeping, and crusting may occur. Lichenification (skin thickening) may predominate in the chronic phase.
To qualify as having atopic dermatitis (Williams et al 1994, Hanifin & Rajka et al 1980), an individual must have (Table 3.1):

- An itchy skin condition in the last 12 months
- Plus three or more of the following:
  
  - Onset before 2 years of age (not applicable in child under 4 years)
  - History of flexural involvement
  - History of generally dry skin
  - History of other atopic disease (or history in first degree relative if child is under 4 years)
  - Visible flexural dermatitis

The eczema is polymorphic, with acute (oozing, or crusted, eroded microvesicles on papular, erythematous plaques), subacute (thicker, paler, somewhat scaly, erythematous, excoriated plaques), and chronic (lichenified, more scaly, hyperpigmented, excoriated, papular plaques) forms. It is not unusual for each stage of evolution to be present at the same time in an individual patient with AD. The dermatitis is more likely to be generalized during infancy and childhood.

AD is a genetically complex disease that has a high familial occurrence. AD is persistent, but relapsing, characterized by exacerbations and remissions.
AD usually presents during early infancy and childhood, but it can persist into or start in adulthood. The lifetime prevalence of AD is 10–20% in children and 1–3% in adults (Ring et al 2004). Its prevalence has increased two- to threefold during the past three decades in industrialized countries but remains much lower in countries with predominantly rural or agricultural areas. Wide variations in prevalence have been observed within countries inhabited by groups with similar genetic backgrounds, suggesting that environmental factors play a critical role in determining expression of AD (Laughter et al 2000, Emerson et al 1998).

AD is the cutaneous manifestation of a systemic disorder that also gives rise to asthma, food allergy, and allergic rhinitis (Leung, et al 2003, Spergel et al 2003). These conditions are all characterized by elevated serum IgE levels and peripheral eosinophilia (Novak et al 2003).

AD is characterized by dry skin and even involves nonlesional skin and increased transepidermal water loss. This impairment of the skin barrier function in AD leads to increased antigen absorption contributing to the cutaneous hyperreactivity characteristic of AD (Sator et al 2003, Chamlin et al 2002).
It has even been proposed that the decreased quantity and quality of maternal touching may affect the child's development, leading to behavioural problems and worsened AD because of life stress (Howlett et al 1999).

Disease severity of AD

In a systematic review of all RCTs of therapeutic interventions for atopic dermatitis (AD) published between 1994 and 2001, Charman et al found that only 27% of the investigators who incorporated an "objective" assessment of clinical severity as an outcome applied a severity scale that had been published before (Charman et al 2003). The authors identified a total of 56 different objective measurements of disease severity in 94 trials (0.6 outcomes per trial).

In 2000, Charman and Williams identified a total of 13 named outcome measurements of disease severity of AD and reported that the vast majority of the measurements identified had not been validated appropriately (Charman et al 2000). The review by Charman focused on the question of whether published outcome measurements had been tested at all and not whether they performed sufficiently well when tested.

In order to reduce the family and psychosocial difficulties associated with AD, researchers and clinicians must first have a clear understanding of the ramifications of the child’s disease severity. Secondly, one must examine how AD impacts different areas of family functioning. Armed with these two pieces
of data, researchers and clinicians can determine the relation between the two (disease severity and family impact) in order to determine whether particular treatments or interventions can help decrease the negative impact of AD on the family (Jayaprakasam et al 2003, Basra et al 2007).

QoL is generally reduced both in inpatients and in outpatients with skin disorders and particularly in patients with AD. The QoL in AD is influenced by a number of factors. Most of the literature contends children’s AD represents a risk factor for their psychosocial well-being. Compared with healthy peers or normal values, children with AD are at greater risk of emotional disorders or behavioural problems (Absolon et al 1997, Daud et al 1993, Meijer et al 2000).

In view of the relevance of this subject, this research was carried out with the objective of assessing the quality of life of infants with AD and their families and also the correlations between the severity of AD.

The Dermatology Department was set up in 1998 in Mid-Western Regional Hospital, Limerick. In an attempt to meet the needs of those children with AD and their caregivers, a dedicated AD clinic was initiated on a twice-monthly basis. Through this clinic, expertise in managing AD developed within the nursing and medical staff. Children with AD seemed to do better within the specialised AD clinic as it allowed parental fears, concerns and treatment desires in relation to their children to be expressed and attended to.
We were mindful that our patients seemed to be benefiting from these clinics but we had not objectively demonstrated that fact. In a health service environment of increased financial rectitude, we felt we had to demonstrate the AD clinics were of benefit to patients and their families.
**Aim**

The aim of our study was to measure the effects of AD on the quality of life (QoL) of affected young children and their families and to see the correlation between the severity of AD and impact on QoL.

We assessed the QoL and severity of the children's eczema using multiple questionnaires on a cohort of patients attending a dedicated paediatric AD clinic.
Methods

The study received ethical approval by the Local Ethics Committee of Mid-Western Regional Hospitals Limerick and was carried out between July and November 2007. All subjects were attending a dedicated paediatric AD clinic in Mid-Western Regional Hospital, Limerick.

At the first visit, a complete medical history was obtained and patients were examined by a consultant Dermatologist (BR) or the Dermatology Specialist Registrar (KA).

A diagnosis of AD was confirmed according to the Hanifin and Rajka’s diagnostic criteria Table 3.1 (Hanifin & Rajka et al 1980). There are different sets of clinical criteria developed for the purpose of making the diagnosis uniformly in different studies as well as in different study centres. One of the most commonly used are Hanifin and Rajka’s set of diagnostic features, which have major and minor clinical criteria to be fulfilled in order to establish a diagnosis of AD which we used Table 3.1.

After seeing the doctor, all patients were assessed by our Dermatology Specialist Nurse and key principles in the management of AD were explained on the first visit.
Although not the prime focus of this study it is worth confirming that the consultation attempted initially to elicit parental *fear and concerns* in relation to their child’s AD and *current and previous treatment used*. The consultation then focused on clearly addressing the parental fears. For example, if fear of topical steroid usage was elicited, it was explored and dealt within an open way allowing the carer to come to understand that topical steroid are safe and effective part of treatment if used properly.

All questionnaires (Table 3.2) were distributed and completed by the parent(s) at first visit before the consultation with the doctor and later at 8 weeks interval. We anticipated that a detailed consultation with Dermatologist and Dermatology Specialist Nurse would show a beneficial effect on control of AD and also on improvement in QoL for both children and parents in a secondary care setting. A formal approval to use IDQoL, DFI and PEOM questionnaire in our study was obtained from the Authors.

Questionnaires were divided in to 2 categories (Table 3.2):

1. Quality of life questionnaires
2. Severity of AD questionnaires
Quality of life questionnaires (QoL)

(a). Infants’ Dermatitis Quality of Life Index (IDQOL)

IDQOL (Table 3.3) was developed in 2001 by Lewis-Jones, Finlay, and Dykes to assess QoL in infants with AD (Lewis-Jones et al 2001). IDQOL is completed by the parents of infants from birth to 4 years.

The instrument consists of 10 questions regarding an infant or young child’s difficulties with mood, sleep, bathing, dressing, play, mealtimes, other family activities, and treatment (Lewis-Jones et al 2001). Each question is graded from 0–3 with a maximum total score of 30. A higher number correlates with a greater impairment of quality of life. An additional question exists that is scored separately on a scale of 0–4 that asks for the parents’ overall assessment of eczema severity.

In the original article the scale was validated with repeatability and sensitivity to change confirmed (Lewis-Jones et al 2001). The scale was further validated with sensitivity to change confirmed and has been used in multiple studies and was published in detail in the Textbook of Paediatric Dermatology (Lewis-Jones 2006).

The IDQOL addresses the impact of the skin condition on domains similar to those of the DLQI (Finlay et al 1994). The specific questions in the IDQOL are framed to be relevant to infant. Scoring is also similar, with response options in
the IDQOL of “not at all” (0), “only a little” (1), “quite a lot” (2), and “very much” (3). Calculation of the IDQOL is the same as that for the DLQI.

(b). Dermatitis Family Impact (DFI)

The parents were asked to complete the Dermatitis Family Impact (DFI) questionnaire (Lawson et al 1998), to assess the impact of AD on the family. The DFI is a disease-specific questionnaire that measures how much AD in children has affected the life of the family over the previous 7 days.

It is based on 10 items: housework, food preparation, sleep of others in the family, leisure activities such as swimming, time spent on shopping, cost related to treatment of AD or clothing, tiredness or exhaustion, emotional distress, relationships in the family, and the impact of helping with treatment on the life of the main caregiver (Table 3.4).

Each question has four answers: not at all = 0, a little = 1, a lot = 2 and very much = 3. The overall summary score aggregates the score of each item and ranges between 0 (the best score) and 30 (the worst score), with higher the score, the poorer the quality of life for the family.

(c). Patient-Oriented Eczema Measure (POEM)

The patient-oriented eczema measure (POEM) is a practical self-assessed measurement tool (Table 3.5) for monitoring aspects of AD that are important to patients in routine clinical practice or in the clinical trial setting and was
completed by parents (Charman et al 2004). Seven symptoms were incorporated in the patient-oriented eczema measure using a simple 5-point scale of frequency of occurrence during the previous week, with a maximum total score of 28.

**Disease severity questionnaires**

**a. Three Item Severity Score (TISS)**

Many different scoring systems have been proposed for assessing the severity of AD (1). These systems are based on the evaluation of 1 or more of the following items: 1) extent; 2) a selection of intensity items; 3) subjective signs (pruritus, sleep loss); and 4) history of eczema.

The SCORAD (SCORing Atopic Dermatitis), one of the best validated systems, is suited for clinical trials, but is too complicated and time consuming for routine clinical use (European Task Force on Atopic Dermatitis 1993).

Severity of AD was scored on a Three Item Severity Score (TISS) which is a simple scoring system based on the sum of 3 intensity items scored on a scale from 0 to 3 (erythema, oedema / papules, excoriations) (Wolkerstorfer et al 1999) was used in this study (Table 3.6).

To minimise the inter-observer variability, a standard figure (figure 3.1) was used showing erythema, oedema / papules, excoriations at different sites. Each item was scored on the most representative lesion. The range of the
TISS score lies between 0 and 9 with higher the score, the more severe the AD.

(b). Parent Global Assessment (PGA) and Doctor Global Assessment (DGA) scores

As a guide to assess the severity of skin diseases, physicians use measurement tools to quantify disease activity. The Patient Global Assessment (PGA) asks a patient to rate on a scale how they severe their skin condition is. The Physician or Doctor Global Assessment (DGA) is a similar item completed by the assessing physician. Both these measures are frequently incorporated into other indices (Gottlieb 2003).

A five-point scale of severity of AD (from 0 as very severe to 4 as completely clear) was also used and completed by the Dermatologist and also by one of the parent(s) of child (Table 3.7)

All children were reviewed and assessed at 8-week interval and all the questionnaires were completed again at second visit (Table 3.2). We anticipated that these might show the beneficial effect for both children and parents of a focused consultation by the dermatology team in a secondary care setting.
Statistical analysis

Total IDQOL and DFI scores and individual question scores were entered on to an Excel (Microsoft) spreadsheet as well as on filemaker pro 8.5 software.

Statistical analysis was carried out using SPSS 15.0.1 statistical software (Inc., San Diego, CA, U.S.A.). The mean and median have been used for parametric and nonparametric data, respectively.

IDQOL and DFI were compared between time-points using the Wilcoxon matched-pairs signed-rank test and groups of different severity were compared using the Mann–Whitney U-test. Correlation of data was analysed using Spearman’s rank correlation coefficient. P < 0.05 was taken as significant.
**Results**

56 children (25M: 31F) with a median age of 23 months (0 - 4 years) participated in the study.

Twenty-seven of 56 (48%) were new referrals, while 29 (51%) were follow-up. Four children had a history of asthma and 45 (80%) children had a family history of atopy.

**Quality of life**

*Infants' Dermatitis Quality of Life Index (IDQOL)*

The mean IDQOL score on first visit was 8.25 (range 1–22) and the mean IDQOL score on second visit dropped to 4.76 (range 0–22). When total score was compared on both visits, p value was significant at 0.004.

The highest score for IDQOL in first visit were *itching and scratching* (question 1, with a mean score of 1.78) which dropped to 1.21 at second visit, *problems at bath time* (question 10, with a mean score of 1.05 which dropped to 0.58), *mood* (*question 2*, *mean of 1.03 at first visit and dropping down to 0.51*), *time taken to get sleep* (question 3, with a mean score of 1.03 dropping to 0.67).

The lowest-scored item was “-Enjoying family activity” (*question 6*, 0.33 which dropped to 0.16). None of the IDQOL items were worse after consultation (Figure 3.2). The detail of IDQOL scores on both visits is given in Table 3.8.
Dermatitis Family Impact (DFI)

The mean DFI score on first visit was 9.07 (range 0–27) and the mean DFI score on second visit dropped to 4.92 (range 0–22). When total score was compared on both visits, p value was significant (p = 0.003).

The highest scores for DFI in first visit were sleep of others in family, (question 3, with a mean score of 1.30) which dropped to 0.76 at second visit, tiredness/exhaustion in parents/carers (question 7, with a mean score of 1.23 which dropped to 0.67), helping with treatment (question 10, mean of 1.17 at first visit and dropping down to 0.71) and costs / expenditure related to treatment, (question 6, with a mean score of 1.10 dropping to 0.67).

The lowest-scored item was ‘time spent shopping’ (question 5, 0.35 which dropped to 0.08). None of the DFI score were worse after consultation (Figure 3.3). The detail of IDQOL scores on both visits is given in Table 3.9.

Patient Oriented Eczema Measure (POEM)

The mean POEM score on first visit was 12.8 (range 0–28) and the mean POEM score on second visit dropped to 7.01 (range 0–21). When total score was compared on both visits, p value was significant (p 0.001).
Severity scores

**Three Item Severity Score (TISS)**

The mean of three items severity score on first visit was 4.44 (0.0 – 9.0) and on review, mean dropped to 2.73 (0.0 – 6.0). When total score was compared on both visits, p value was significant (p 0.001). TISS was improved after the intervention. When TISS score was compared with the IDQOL and DFI, it correlated confirming severity was directly related and has more impact on quality of life not only infant but also the family.

**Patient global assessment score (PGA)**

The mean PGA score on first visit was 2.03 (range 0–4) and the mean PGA score on second visit improved to 2.96 (range 2–4). When the total score was compared on both visits, the p value was significant at 0.001.

**Doctor Global Assessment (DGA) scores**

The mean DGA score on first visit was 2.30 (range 0–4) and the mean DGA score on second visit improved to 3.03 (range 2–4). When the total score was compared on both visits, the p value was 0.001.

When PGA scores were compared with DGA, doctors' scores were higher although the p value was not significant. When the IDQOL at first and second visits was compared with DFI, there was a positive correlation with a p value
of 0.001, confirming that children with high scores of IDQOL had a higher impact on their families and vice versa.

Similarly when severity of AD (TISS) was compared with IDQOL, there was a positive correlation confirming that severity of AD was directly correlated on children's quality of life. Children with highest scoring IDQOL showed very high scores of DFI and TISS confirming that there is a positive correlation between the severity of AD with impact on the child and his family. The findings are shown in figure 3.4 to 3.12.

10 highest scores for IDQOL, DFI and TISS

When we looked at the ten infants with highest scores of IDQOL, their DFI scores were also comparatively high. Similarly highest TISS and DFI scores showed a similar trend. This confirmed that infants with highest IDQOL scores, had more severe disease and more impact on the family.
Discussion

Knowledge of the relative impact of AD on QoL is important, as morbidity rather than mortality is the primary concern in AD management, as is the case with many other chronic dermatologic conditions. Establishment of the degree of QoL impairment in patients with AD will help managed care decision-makers decide the amount of resources to allocate for its management.

In addition, drug therapies targeting AD should be evaluated in terms of how they affect burden of illness. Despite the fact that AD typically starts in infancy, little attention has been paid to the impact it has on parents.

Quality of life (QoL) has become a catchphrase in the medical profession and has many dimensions. It is scientifically measurable with validated tools and can be used to compare disability between different dermatoses or to assess the degree of handicap of patients with dermatoses against those with other illnesses (Lewis-Jones et al 2001).

This study provides further validation of the IDQOL and the DFI in infants and confirms their sensitivity to clinical change from the parent’s perspective. In our study, the median IDQOL score on first visit is 7, which compares well with previous study’s median score of 8 (Beattie et al 2006).

Similarly, the three highest-scoring IDQOL items (itching and scratching, problems at bath time and time taken to fall asleep) are exactly the same in our
study and as in the study by Beattie et al (2006). However, in the original report of the IDQOL by Lewis Jones et al, mood changes and itching were two of the three highest-scoring items (Lewis-Jones et al 2001). The least scoring items (enjoying family activity) was same in our and the previous study.

The median score for DFI on first visit was 8 with the three highest scores being sleep disturbance among others in the family, tiredness and exhaustion and helping with treatment. Beattie et al reported tiredness and exhaustion, sleep and emotional distress as the highest scoring items in the DFI in this study, while in the original DFI study, problems caused by the child’s treatment scored the highest (Beattie et 2006, Basra et al 2007).

We have found mean IDQOL and DFI scores to be similar to those described previously and have also confirmed a high correlation between these measurement tools (Lewis-Jones et al 2001). In addition, we have shown that the highest-scoring items of both measures were those that correlated most strongly with eczema severity.

Our study is a further confirmation that there is significant morbidity associated with AD and it has a negative impact on QoL on the child, caregiver and family as measured by the QoL measures and severity scores used in this study. The baseline IDQOL and DFI data shows this morbidity to range through multiple facets of the child and family life.
The adverse effect on the individual is all-pervasive affecting social activities, mealtimes and sleep. The effect is far reaching for the family with adverse impact on the family leisure, tiredness, expenditure and emotional distress.

The follow up QoL and severity data confirmed improvement in QoL and the doctor-assessed severity score reduced by 8 weeks after the initial consultation.

TISS and DGA have been shown to correlate with QoL measured by the DFI and the IDLQI, which demonstrate that they are sensitive to change in clinical severity. Similar to our findings, most studies have shown the magnitude of adverse effects on the family to increase with the severity of childhood AD (Pauli-Pott et al 1999, Su et al 1997, Basra 2007).

The consultation focused on five issues we have particularly identified as being of beneficial for children with AD. These included:

1. Regular emollient baths
2. Adequate anti-inflammatory therapy ie topical steroids, topical tacrolimus
3. Appropriate emollients
4. Appropriate anti-infective agents if required ie bleach baths, topical or oral antibiotics
5. Specialised techniques ie wet wraps and bandages

These areas were supported by a comprehensive consultation by the Dermatologist and the dermatology specialist nurse completing the consultation making sure that all the factors have been addressed.

Role of nursing in management of AD

With the increasing prevalence of AD in children and its impact on the QoL of both the child and the family, optimal management of this chronic illness is paramount. According to the literature the most effective way to manage AD is to provide time for education and demonstration of a comprehensive range of treatments (Nicol 2005, http://www.nice.org.uk/media/AtopicEczema APP).

This management cannot be achieved alone in dermatologist-led clinics due to time constraints placed on doctors. Nurse-led clinics have been shown to allow increased time to be spent with patients, resulting in greater patient education, adherence to treatments and increased satisfaction with care.

Whatever the treatment, poor adherence is a major cause of treatment failure in AD (Hoare et al 2000). The difficulties in managing a chronic illness such as AD are well recognized in the literature (Zuberbier et al 2006). Treatment regimens for chronic illnesses are often complex and require the patient, parent or carer to implement treatments at home for extended periods (Lubikin et al 2002).
Chronic illness management requires long-term self-care and as AD is predominately a disease of early childhood, parental participation is critical in the management of AD treatments. Age related educational programmes for the control of atopic dermatitis in children and adolescents are effective in the long term management of the disease (Staab 2006).

The contribution of nursing to patient care through nurse-led clinics has significant potential in the management of many common chronic illnesses; AD has received minimal attention to date. Cork et al found that after the intervention by the advanced practice nurse, the patients received at least two hour of listening, explanation and demonstration of therapies, in contrast with six minutes available for the average general practitioner consultation (Cork et al 2003). A control group was not used in this and therefore the authors were not able to determine if consultation time was correlated to patient outcomes.

Kinnersley et al found that patients who consulted nurse practitioners were generally more satisfied with their care (Kinnersley et al 2000). It is well known that poor patient satisfaction can lead to poor compliance and consequently a poor outcome of treatment (Renzi et al 2001).

A key advantage of nurse-led clinics is the length of time between the advanced practice nurse and patient/carer and patients reported being provided with more information (Kinnersley et al 2000).
Use of the IDQOL and DFI demonstrated that infants with eczema have the greatest problems with itching, sleep loss, mood, and behavioural changes. Infant AD has a profound impact on the emotional and social well-being of the parents. Our results demonstrated the importance of having a dedicated clinic for AD with improvements observed in QOL measures after 1 visit.

Although, there has been more awareness on QoL in skin disease over last few years, there is still a need for future research to address those gaps, which exist in the field. Particularly, research is needed into the effectiveness of enhancing patients’ coping strategies through psychological counselling, efficacy of different psychological interventions and treatment at different stages of the illness.

We have found our dedicated AD clinic allows us to focus on the impact of the disease on both child and family. Knowledge of the high scoring items on QoL questionnaire has enabled us to target these factors in our consultations.
Conclusions

Our results show that family life was markedly disrupted by having a child with eczema. Intervention programmes for parents with a child suffering from AD should therefore include elements which aim to improve their psychosocial well-being (e.g. stress management techniques).

The evidence suggests that interventions which merely reduce the intensity of AD symptoms are insufficient to improve parental disease management as their psychosocial and familial situation has to be considered as well.

Our study showed that there is significant morbidity associated with AD with a significant impact on QoL for the child, caregiver and family. A significant improvement occurred across the QoL and severity measures used and this confirms that attendance at a specialist clinic is of benefit to the patients and their families.

It is supportive data to develop the service further and provides evidence for service planners that this is a service worth supporting. Optimising control for patients with atopic dermatitis reduces their symptoms and is more likely to reduce expensive hospital admissions.
<table>
<thead>
<tr>
<th>Major criteria</th>
<th>Minor criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>(3 of 4 present)</td>
<td>(3 of 23 present)</td>
</tr>
<tr>
<td>Pruritus</td>
<td>Xerosis</td>
</tr>
<tr>
<td>typical morphology and distribution of skin lesions</td>
<td>ichthyosis/palmar hyperlinearity/keratosis pilaris</td>
</tr>
<tr>
<td>chronic or chronically relapsing dermatitis</td>
<td>immediate (type I) skin test reactivity</td>
</tr>
<tr>
<td>personal or family history</td>
<td>elevated serum IgE</td>
</tr>
<tr>
<td></td>
<td>early age of onset</td>
</tr>
<tr>
<td></td>
<td>tendency towards cutaneous infections/impaired cell-mediated immunity</td>
</tr>
<tr>
<td></td>
<td>tendency towards non-specific hand or foot dermatitis</td>
</tr>
<tr>
<td></td>
<td>nipple eczema</td>
</tr>
<tr>
<td></td>
<td>cheilitis</td>
</tr>
<tr>
<td></td>
<td>recurrent conjunctivitis</td>
</tr>
<tr>
<td></td>
<td>Dennie-Morgan infraorbital fold</td>
</tr>
<tr>
<td></td>
<td>keratoconus</td>
</tr>
<tr>
<td></td>
<td>anterior subcapsular cataracts</td>
</tr>
<tr>
<td></td>
<td>orbital darkening</td>
</tr>
<tr>
<td></td>
<td>facial pallor/erythema</td>
</tr>
<tr>
<td></td>
<td>pityriasis alba</td>
</tr>
<tr>
<td></td>
<td>anterior neck folds</td>
</tr>
<tr>
<td></td>
<td>itch when sweating</td>
</tr>
<tr>
<td></td>
<td>intolerance to wool and lipid solvents</td>
</tr>
<tr>
<td></td>
<td>perifollicular accentuation</td>
</tr>
<tr>
<td></td>
<td>food intolerance</td>
</tr>
<tr>
<td></td>
<td>course influenced by environmental/emotional factors</td>
</tr>
<tr>
<td></td>
<td>white dermographism/delayed blanch</td>
</tr>
</tbody>
</table>
Table 3.2: List of questionnaires used in the study

<table>
<thead>
<tr>
<th>Quality of life (QoL) of measures</th>
<th>Severity scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Infants' Dermatitis Quality of Life Index (IDQOL)</td>
<td>1. Three Item Severity Score (TIISS)</td>
</tr>
<tr>
<td>2. Dermatitis Family Impact (DFI)</td>
<td>2. Patient Global Assessment (PGA) and Doctor Global Assessment (DGA) scores: five point scale with 0 as very severe to 4 as completely clear by parents and the by Doctor</td>
</tr>
<tr>
<td>3. Patient Oriented Eczema Measure (POEM)</td>
<td></td>
</tr>
</tbody>
</table>


Table 3.3
Infant Dermatology quality of life index (IDQOL)

<table>
<thead>
<tr>
<th>Dermatitis Severity</th>
<th>Over the last week, how severe do you think your child’s dermatitis has been?; i.e. how red, scaly, inflamed or widespread.</th>
<th>Extremely severe</th>
<th>Severe</th>
<th>Average</th>
<th>Fairly good</th>
<th>None</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life Quality Index</td>
<td>1. Over the last week, how much has your child been itching and scratching?</td>
<td>All the time</td>
<td>A lot</td>
<td>A little</td>
<td>None</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2. Over the last week, what has your child’s mood been?</td>
<td>extremely difficult</td>
<td>Very fretful</td>
<td>Slightly fretful</td>
<td>Happy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3. Over the last week approximately how much time on average has it taken to get your child off to sleep each night?</td>
<td>More than 2 hrs</td>
<td>1 - 2 hrs</td>
<td>5mins - 1 hr</td>
<td>0-15mins</td>
<td></td>
</tr>
<tr>
<td></td>
<td>4. Over the last week, what was the total time that your child’s sleep was disturbed on average each night?</td>
<td>5 hrs or more</td>
<td>3 - 4 hrs</td>
<td>1 - 2 hrs</td>
<td>Less than 1 hour</td>
<td></td>
</tr>
<tr>
<td></td>
<td>5. Over the last week, has your child’s eczema interfered with playing or swimming?</td>
<td>Very much</td>
<td>A lot</td>
<td>A little</td>
<td>Not at all</td>
<td></td>
</tr>
<tr>
<td></td>
<td>6. Over the last week, has your child’s eczema interfered with your child taking part in or enjoying other family activities?</td>
<td>Very much</td>
<td>A lot</td>
<td>A little</td>
<td>Not at all</td>
<td></td>
</tr>
<tr>
<td></td>
<td>7. Over the last week, have there been problems with your child at mealtimes because of the eczema?</td>
<td>Very much</td>
<td>A lot</td>
<td>A little</td>
<td>None</td>
<td></td>
</tr>
<tr>
<td></td>
<td>8. Over the last week, have there been problems with your child caused by the treatment?</td>
<td>Very much</td>
<td>A lot</td>
<td>A little</td>
<td>None</td>
<td></td>
</tr>
<tr>
<td></td>
<td>9. Over the last week, has your child’s eczema meant that dressing and undressing the child has been uncomfortable?</td>
<td>Very much</td>
<td>A lot</td>
<td>A little</td>
<td>None</td>
<td></td>
</tr>
<tr>
<td></td>
<td>10. Over the last week how much has your child having eczema been a problem at bathtime?</td>
<td>Very much</td>
<td>A lot</td>
<td>A little</td>
<td>None</td>
<td></td>
</tr>
</tbody>
</table>

Formal permission was obtained to use this Questionnaire in this study
Table 3.4

Dermatitis Family Impact Questionnaire (DFI)

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Over the last week, how much effect has your child having eczema had on housework, e.g. washing, cleaning.</td>
<td>Very much ☐</td>
</tr>
<tr>
<td></td>
<td>A lot ☐</td>
</tr>
<tr>
<td></td>
<td>A little ☐</td>
</tr>
<tr>
<td></td>
<td>Not at all ☐</td>
</tr>
<tr>
<td>2. Over the last week, how much effect has your child having eczema had on food preparation and feeding.</td>
<td>Very much ☐</td>
</tr>
<tr>
<td></td>
<td>A lot ☐</td>
</tr>
<tr>
<td></td>
<td>A little ☐</td>
</tr>
<tr>
<td></td>
<td>Not at all ☐</td>
</tr>
<tr>
<td>3. Over the last week, how much effect has your child having eczema had on the sleep of others in family.</td>
<td>Very much ☐</td>
</tr>
<tr>
<td></td>
<td>A lot ☐</td>
</tr>
<tr>
<td></td>
<td>A little ☐</td>
</tr>
<tr>
<td></td>
<td>Not at all ☐</td>
</tr>
<tr>
<td>4. Over the last week, how much effect has your child having eczema had on family leisure activities, eg swimming.</td>
<td>Very much ☐</td>
</tr>
<tr>
<td></td>
<td>A lot ☐</td>
</tr>
<tr>
<td></td>
<td>A little ☐</td>
</tr>
<tr>
<td></td>
<td>Not at all ☐</td>
</tr>
<tr>
<td>5. Over the last week, how much effect has your child having eczema had on time spent on shopping for the family.</td>
<td>Very much ☐</td>
</tr>
<tr>
<td></td>
<td>A lot ☐</td>
</tr>
<tr>
<td></td>
<td>A little ☐</td>
</tr>
<tr>
<td></td>
<td>Not at all ☐</td>
</tr>
<tr>
<td>6. Over the last week, how much effect has your child having eczema had on your expenditure, eg costs related to treatment, clothes, etc.</td>
<td>Very much ☐</td>
</tr>
<tr>
<td></td>
<td>A lot ☐</td>
</tr>
<tr>
<td></td>
<td>A little ☐</td>
</tr>
<tr>
<td></td>
<td>Not at all ☐</td>
</tr>
<tr>
<td>7. Over the last week, how much effect has your child having eczema had on causing tiredness or exhaustion in your child’s parents/carers.</td>
<td>Very much ☐</td>
</tr>
<tr>
<td></td>
<td>A lot ☐</td>
</tr>
<tr>
<td></td>
<td>A little ☐</td>
</tr>
<tr>
<td></td>
<td>Not at all ☐</td>
</tr>
<tr>
<td>8. Over the last week, how much effect has your child having eczema had on causing emotional distress such as depression, frustration or guilt in your child’s parents/carers.</td>
<td>Very much ☐</td>
</tr>
<tr>
<td></td>
<td>A lot ☐</td>
</tr>
<tr>
<td></td>
<td>A little ☐</td>
</tr>
<tr>
<td></td>
<td>Not at all ☐</td>
</tr>
<tr>
<td>9. Over the last week, how much effect has your child having eczema had on relationships between the main carer and partner or between the main carer and other children in the family.</td>
<td>Very much ☐</td>
</tr>
<tr>
<td></td>
<td>A lot ☐</td>
</tr>
<tr>
<td></td>
<td>A little ☐</td>
</tr>
<tr>
<td></td>
<td>Not at all ☐</td>
</tr>
<tr>
<td>10. Over the last week, how much effect has helping with your child’s treatment had on the main carer’s life.</td>
<td>Very much ☐</td>
</tr>
<tr>
<td></td>
<td>A lot ☐</td>
</tr>
<tr>
<td></td>
<td>A little ☐</td>
</tr>
<tr>
<td></td>
<td>Not at all ☐</td>
</tr>
</tbody>
</table>

Formal permission approved to use this Questionnaire in this study
Table 3.5

Patient-Oriented Eczema Measure (POEM)

1. *Over the last week,* on how many days has your / your child's skin been itchy because of the eczema?
   
<table>
<thead>
<tr>
<th>No Days</th>
<th>1-2 Days</th>
<th>3-4 Days</th>
<th>5-6 Days</th>
<th>Every Day</th>
</tr>
</thead>
</table>

2. *Over the last week,* on how many nights has your / your child's sleep been disturbed because of the eczema?
   
<table>
<thead>
<tr>
<th>No Days</th>
<th>1-2 Days</th>
<th>3-4 Days</th>
<th>5-6 Days</th>
<th>Every Day</th>
</tr>
</thead>
</table>

3. *Over the last week,* on how many days has your / your child's skin been bleeding because of the eczema?
   
<table>
<thead>
<tr>
<th>No Days</th>
<th>1-2 Days</th>
<th>3-4 Days</th>
<th>5-6 Days</th>
<th>Every Day</th>
</tr>
</thead>
</table>

4. *Over the last week,* on how many days has your / your child's skin been weeping or oozing clear fluid because of the eczema?
   
<table>
<thead>
<tr>
<th>No Days</th>
<th>1-2 Days</th>
<th>3-4 Days</th>
<th>5-6 Days</th>
<th>Every Day</th>
</tr>
</thead>
</table>

5. *Over the last week,* on how many days has your / your child's skin been cracked because of the eczema?
   
<table>
<thead>
<tr>
<th>No Days</th>
<th>1-2 Days</th>
<th>3-4 Days</th>
<th>5-6 Days</th>
<th>Every Day</th>
</tr>
</thead>
</table>

6. *Over the last week,* on how many days has your / your child's skin been flaking off because of the eczema?
   
<table>
<thead>
<tr>
<th>No Days</th>
<th>1-2 Days</th>
<th>3-4 Days</th>
<th>5-6 Days</th>
<th>Every Day</th>
</tr>
</thead>
</table>

7. *Over the last week,* on how many days has your / your child's skin felt dry or rough because of the eczema?
   
<table>
<thead>
<tr>
<th>No Days</th>
<th>1-2 Days</th>
<th>3-4 Days</th>
<th>5-6 Days</th>
<th>Every Day</th>
</tr>
</thead>
</table>

**Total Score (maximum 28) =**

*Formal permission approved to use this Questionnaire in this study*
Table 3.6: Three point scoring system (TISS)

Enter an "X" in the appropriate column for each finding (give only 1 answer per row)

<table>
<thead>
<tr>
<th>Signs</th>
<th>None=0</th>
<th>Mild=1</th>
<th>Moderate=2</th>
<th>Severe=3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Erythema</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Excoriations</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oedema and / or papulations</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Total score (out of 9):

Formal permission approved to use this Questionnaire in this study
Table 3.7 Doctor global assessment

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Severe</td>
<td>Moderate to severe</td>
<td>Mild to moderate</td>
<td>Mild</td>
<td>Completely clear</td>
<td></td>
</tr>
</tbody>
</table>

Table 3.8: IDQOL results as both visits (score range 0-3)

<table>
<thead>
<tr>
<th>Question</th>
<th>Mean IDQOL score 1st visit</th>
<th>Mean IDQOL score 2nd visit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Itching and scratching</td>
<td>1.78</td>
<td>1.21</td>
</tr>
<tr>
<td>Mood</td>
<td>1.03</td>
<td>0.51</td>
</tr>
<tr>
<td>Time to get to sleep</td>
<td>0.98</td>
<td>0.67</td>
</tr>
<tr>
<td>Total time disturbed</td>
<td>0.89</td>
<td>0.51</td>
</tr>
<tr>
<td>Playing or swimming</td>
<td>0.41</td>
<td>0.19</td>
</tr>
<tr>
<td>Enjoying family activity</td>
<td>0.33</td>
<td>0.16</td>
</tr>
<tr>
<td>Mealtimes</td>
<td>0.39</td>
<td>0.19</td>
</tr>
<tr>
<td>Problems from treatment</td>
<td>0.57</td>
<td>0.32</td>
</tr>
<tr>
<td>Dressing uncomfortable</td>
<td>0.76</td>
<td>0.37</td>
</tr>
<tr>
<td>Problems at bath time</td>
<td>1.05</td>
<td>0.58</td>
</tr>
</tbody>
</table>
Table 3.9: DFI scores at both visits  (score range 0-3)

<table>
<thead>
<tr>
<th>Question</th>
<th>Mean DFI score 1&lt;sup&gt;st&lt;/sup&gt; visit</th>
<th>Mean DFI score 2&lt;sup&gt;nd&lt;/sup&gt; visit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Housework</td>
<td>0.98</td>
<td>0.58</td>
</tr>
<tr>
<td>Food preparation/feeding</td>
<td>0.75</td>
<td>0.44</td>
</tr>
<tr>
<td>Sleep of others in family</td>
<td>1.30</td>
<td>0.76</td>
</tr>
<tr>
<td>Family leisure activity</td>
<td>0.60</td>
<td>0.30</td>
</tr>
<tr>
<td>Time spent shopping</td>
<td>0.35</td>
<td>0.08</td>
</tr>
<tr>
<td>Expenditure</td>
<td>1.10</td>
<td>0.67</td>
</tr>
<tr>
<td>Tiredness/exhaustion</td>
<td>1.23</td>
<td>0.67</td>
</tr>
<tr>
<td>Emotional distress</td>
<td>0.89</td>
<td>0.42</td>
</tr>
<tr>
<td>Relationships</td>
<td>0.71</td>
<td>0.30</td>
</tr>
<tr>
<td>Helping with treatment</td>
<td>1.17</td>
<td>0.71</td>
</tr>
</tbody>
</table>
Figure 3.1

Three point scoring system (TISS) reference picture used to score
Figure 3.2: IDQOL scores before and after intervention at visit 1 and visit 2
Figure 3.3: DFI scores before and after intervention at visit 1 and visit 2
Figure 3.4: Effect of treatment on infant QoL (median shown as horizontal line) at 1\textsuperscript{st} and 2\textsuperscript{nd} visit

Figure 3.5: Effect of treatment on DFI (median shown as horizontal line) at 1\textsuperscript{st} and 2\textsuperscript{nd} visit
Figure 3.6: Effect of treatment on TISS (median shown as horizontal line) at 1\textsuperscript{st} and 2\textsuperscript{nd} visit
Figure 3.7: positive correlation between IDQOL and DFI at 1\textsuperscript{st} visit

Figure 3.8: positive correlation between IDQOL and DFI at 2\textsuperscript{nd} visit
Figure 3.9: positive correlation between IDQOL and TISS at 1\textsuperscript{st} visit

Figure 3.10: positive correlation between IDQOL and TISS at 2\textsuperscript{nd} visit
Figure 3.11: positive correlation between DFI and TISS at 1\textsuperscript{st} visit

Figure 3.12: positive correlation between DFI and TISS at 2\textsuperscript{nd} visit
CHAPTER 4

Patients Fears and Expectations: Exploring the Hidden Agenda in the Dermatologic Consultation
Introduction

Questionnaires like the dermatology life quality index (DLQI) are important in quantifying the psychological and social impact of skin disease on patients and tend to focus on the inflammatory skin diseases (Finlay et al 1994). Patients with inflammatory and non-inflammatory skin conditions have fears, therapeutic expectations and varying levels of understanding about their skin condition. These aspects may be ignored or over-looked in many consultations, while the Dermatologist tends to focus on diagnosis and treatment.

Studies of patients’ beliefs and expectations accompanying participation in decision-making preferences within the context of specific healthcare treatments are limited. The relationship between doctor and patient has long been viewed in terms such as compliance which reflect primarily the influence of the doctor. Patient satisfaction is another important measure in health services research (Treadway et al 1983, Feletti et al 1986). It is seen as a measure of outcome that can be used to evaluate treatment.

Patient satisfaction is an important and commonly used indicator for measuring quality in health care. Patient satisfaction affects clinical outcomes, patient retention, and medical malpractice claims. It affects the timely, efficient, and patient-centered delivery of quality health care. Patient satisfaction is thus a proxy but a very effective indicator to measure the success of doctors and hospitals (Paul GA et al 2008, Renzi C et al 2001).
To consider patients' satisfaction is only one component of a "consumer" orientation. Arguably more fundamental is to understand what their expectations are when they visit the doctor. This has been relatively neglected in the literature by comparison with satisfaction, but its importance is shown by studies which have suggested a lack of perception by doctor of patients' intentions when attending for consultation (Taylor et al 1979, Kindelan et al 1986). It has been shown that a higher patient satisfaction is related to better compliance with advice on treatment.

Over recent years there has been an increasing emphasis on the patient as a consumer and patients are being increasingly encouraged to take a central role in the decision making process of the consultation (Good et al 1983). Doctors need to be aware of how much the patient wants to participate in decision-making. Patients differ in the degree they wish to participate in their medical care.

If the doctor encourages the patient to have an input into the decision making process than the patient will better adjust to the treatment regimen as well as be more satisfied with the treatment (Auerbach et al 1983, Martelli et al 1987, Mahler et al 1991).

If the patient wants to take part in decision making, but the doctor wants to make all the decisions, without finding out the patient's opinion, then there may be much conflict. If the patient wants the doctor to make all of the decisions,
but the doctor wants participation then this causes the patient to feel uncomfortable. This mismatch between the doctor and patient will cause the patient stress (Miller et al 1983).

The measurement of patients' concern is complex in view of evidence that patient does not merely present with presenting symptoms, but also their concerns related to symptoms and their need for explanation of the condition (Ingham et al 1986). Simple categorization of intentions according to medical condition is therefore inadequate.

One approach to identifying these concerns and satisfaction is by analysing patients' responses to a questionnaire on which they identified their specific fears and concerns. We therefore, proposed using a novel tool to explore the impact of skin disease from the perspective of patient's fears and level of understanding of their condition, their expectations from consultation and their level of satisfaction following the consultation.

The second purpose of this study was therefore to use patients' scores on each of the dimensions emerging from analysis of the questionnaire to investigate the relationship between their concerns and the types of specialist or other service which they envisage being of use. Specifically, we examined whether any dimension of intentions to seek emotional support would be associated with expectation of help from specialist psychiatric services.
Methods

A prospective questionnaire based study performed from January 2007 to September 2007 at Dermatology Department in Mid-western Regional Hospital, Limerick, Ireland. The study was approved by the local ethics committee of Midwestern Regional Hospitals,

Patients were given two questionnaires with open-ended questions.

**Questionnaire 1**

This was completed by patients immediately before the consultation. Patients were given three open ended questions aimed at eliciting their level of understanding about their skin condition, any fears or worries related to their condition and finally what did they want from the Doctor that day (Table 4.1). The Doctor was blinded to the answers of questionnaire 1.

**Questionnaire 2**

The second questionnaire was given immediately after the consultation which included two questions about the level of satisfaction of their visit (Table 4.1). The Doctor checked the patient’s written responses once the consultation is finished and when the patient had left.

The data was collected over a 9 month period from January 2007 to September 2007. Patients attending the dermatology outpatient clinic were informed about the study by a doctor / dermatology nurse specialists. Those consenting were given two questionnaires to complete and asked to return
them after the consultation. Children who were attending with parents were included and were asked to complete the questionnaire. Patients who could not complete the questionnaire on their own were helped by the dermatology nurse.

The other data collected included: age, sex, new or review patient, and final diagnosis. The patient's diagnosis was also categorised broadly into inflammatory and non-inflammatory diseases. If it was a non-inflammatory disease, then it was further divided into benign and malignant disease. The data was stored on FileMaker Pro 8.5 database software.
Results

Questionnaires were given to 750 patients attending the dermatology outpatient clinic. Completed questionnaires were received from 678 patients (male 271 and female 407, age range 1 – 93 years with a mean of 52 years). There were 69 children range 1-10 years and their questionnaire were completed by their parents. 72 questionnaires were partially completed and were rejected. The final response rate was 90% with 678 questionnaires being analysed.

472 patients were new patients and 206 were review patients. 363 patients had inflammatory disease while 315 had non-inflammatory disease. Out of 315, 219 (69%) had benign lesions and 96 (31%) had malignant lesions. 323 (48%) of patients had a single fear, 276 (40%) had multiple fears and 79 patients (11%) reported "no fears" relating to their skin condition. Results are divided into three groups:

1. Patient's fears
2. Patient's expectations
3. Post consultation satisfaction

Patient's fears

There were 9 different categories of fears based on words used by the patients (Table 4.2). The commonest categories were fear of cancer (28%), symptoms (25%), persistence of condition (24%), future deterioration of the condition (23%), and unsightly (13%). Fear of infectivity and fear of scarring were the
lowest scoring fears. 79 patients (11%) reported “no fears” relating to their skin condition (inflammatory diseases 22, benign lesion 34, and skin cancer 23). Fear of cancer was more common in male patients (145 of 271) compared to females (46 of 407). Fear of cancer was present in 175 patients presenting with lesions and in 16 patients with inflammatory disorders.

Multiple fears were more common in review patients (158) compared to new patients (118). 143 Patients with inflammatory dermatoses have single fear. Multiple fears were also common in patients with inflammatory dermatoses (212) compared with patients attending for lesion check up (43). The Doctor was unaware of the patient's fears in 32% of consultations.

**Patient's expectations**

There were nine categories of response in terms of patient's expectations (Table 4.3). More than one third (38%) patients had multiple expectations. The commonest expectation was for “reassurance” and “advice” (42%) followed by “looking for treatment” i.e. control of their skin condition (40%), and “seeing diagnosis” (17%). 61 (8%) patients (male 25, female 36) had unrealistic expectations e.g. looking for cure in a condition in which a cure was not available.

The doctor was not aware of the patient's expectations in 102 patients (15%). The desire for cure (eradication of disease) was mentioned by 10% and in the
majority (90%) of these cases, it was in patients with incurable inflammatory dermatoses i.e. psoriasis, eczema, lupus and hidradenitis suppurativa.

**Post Consultation Satisfaction**

95% were satisfied or very satisfied with the consultation. However, 4% felt no change (27 inflammatory, 2 non-inflammatory) and 1% had unresolved fears after the consultation. 23% of patients with inflammatory disorders wanted ongoing care by the team.

19% were hopeful for future improvement. 10 patients (1%) felt worse after the consultation when they became aware that they had either a chronic skin disease or skin cancer.

Eight patients (0.9%) who had chronic inflammatory skin disease were still looking for cure after the consultation even though they were told that there was no cure.
Discussion

Patients have a wide range of fears about their skin condition and these are often multiple and unexpressed. Moreover, patients' fears are sometimes directly influenced and exaggerated by the information they have gathered from other sources; e.g., the internet.

By using the simple questionnaire, a range of fears and expectations can be highlighted. It augments the consultation by enabling both the patient and doctor to see exactly what the patient is currently worried about in relation to their skin condition at that time. This in turn allows the consultation to focus on those fears and expectations – possibly resulting in a more positive consultation for the patient.

It also shows to the patient that the doctor is interested in them as a person, not just as someone with a disease. If these fears are not elicited, expressed by the patients and dealt with in the consultation, they remain and possibly may multiply - more review patients had multiple fears than new patients in our study. Our patients acknowledged and appreciated that these questions were asked as it had helped them express their fears.

Patients with inflammatory dermatoses have more multiple fears and multiple expectations compared to patients who were attending with a diagnosis of non-inflammatory dermatoses (lesions). Table 4.4 shows some
examples of the clear language used by our patients to describe their fears and expectations.

Previous studies have described the importance of giving information, good communication, being listened to, and having choices over how patients are managed (Coulter et al 1999, Salmon et al 1989). In line with this, we also looked at patients' expectations and satisfaction from the consultation.

To explore fully the relationships between expectations and satisfaction, it was important that expectations were assessed before patients see a doctor, as in our study, to avoid confounding the assessment of satisfaction because it was generally assumed that responders use the opportunity to complain.

The expectations varied among patients as patients with inappropriately high expectations may be dissatisfied with optimal care, and those with low expectations may be satisfied with deficient care. In a busy clinic, the doctor may not be fully aware of patient’s expectation for the visit.

In our study, the doctor was unaware of patient’s expectations in 15% of cases. We also noticed that patients with multiple fears had multiple expectations (23% of patients) reflecting that multiplicity was directly proportional as far as fears and expectations are concerned. Only 3% of patients with a single fear had multiple expectations.
Despite the doctor’s explanation and reassurance about the relatively low risks of skin cancers, 17 patients (2%) were not convinced and had persistent fear of skin cancers asking for removal of benign lesions (for an example see response 3, Table 4.4).

Patient’s views have become an important element in the evaluation of health care, even though the concept of patient satisfaction has rarely been defined. There are several existing measures of patient experiences of care in the form of satisfaction scales (Ware et al 1983, Wolf et al 1978). Although most of the patients (95%) in our study expressed moderate or high level of satisfaction, it is important to highlight that in the context of patient satisfaction literature, most respondents express positive satisfaction.

One possible reason for these high levels of satisfaction is that patients are reluctant to criticise health professionals - the so-called normative effect. These results suggest that if a doctor wishes to improve the care of patients then evaluating his or her effectiveness may be more complicated than simply handing out a validated measure of the patient’s experience without first assessing and understanding the patient’s expectations.

Given these caveats, the results do provide some insights into patients’ experiences and expectations of hospital practice. Although most patients had their expectations met at a moderate or high level, 5% (39 patients) had unresolved fears or they felt no change as far as their fears are concerned.
Limitations of the study

We focused on sequential dermatology outpatients but without a ‘control’ group to compare our findings. We had to perform this study, in a sense, unblinded ie you would expect the study doctors to elicit the patients fears and expectations. However, even allowing for its unblinded nature, the study doctors were unaware of patient’s fears in a third of cases.

No formal validation of the questionnaire was done which is also a limitation of the study. We do not know from this study if patient's fears / expectations of treatment remain rigid or fixed over time.

Strengths of the study

The strengths of this study are that it elicits the wide range of fears and treatment expectations that patient have. Because the questionnaire is short, easy to fill in and was completed by >90% of patients, it takes a short time to administer and complete it.

Many of the patients commented favourably on being asked to fill in the answers, as they were aware it helped them express what was bothering them. As the questions are open-ended, the resultant answers are in patient’s own words and this gives powerful clear information for the doctor and patient to work together.
Conclusions

We feel that we have developed a short and easy to administer questionnaire through which the range of fears and expectations experienced by patients attending dermatology outpatients can be highlighted.

Our results provide helpful insight into the variation of fears and treatment expectations of patients with common skin diseases in our general population.

This could prove to be a useful tool in the improvement of health services which can be effectively used to improve quality of care. In addition to this questionnaire, DLQI (Finlay et al 1994) and other skin specific diseases oriented questionnaires or scales can help to add to enhance the consultation and enable collaborative treatment planning with the patients.
Table 4.1: Questionnaire 1 and 2

<table>
<thead>
<tr>
<th>Questionnaire 1:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What fears / worries do you have about your skin condition?</td>
</tr>
<tr>
<td>2. What do you think is the problem with your skin?</td>
</tr>
<tr>
<td>3. What do you want from doctor today?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Questionnaire 2:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How do you feel about having expressed your fears / worries about your skin condition today?</td>
</tr>
<tr>
<td>2. What more do you want from us if we could provide it for your skin condition?</td>
</tr>
</tbody>
</table>
Table 4.2: Categories of fear (with number of patients) Total = 678

<table>
<thead>
<tr>
<th>Category</th>
<th>Number of Patients</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer Symptoms</td>
<td>191</td>
<td>28%</td>
</tr>
<tr>
<td>Persistent</td>
<td>171</td>
<td>25%</td>
</tr>
<tr>
<td>Future deterioration</td>
<td>160</td>
<td>24%</td>
</tr>
<tr>
<td>Unsightly</td>
<td>156</td>
<td>23%</td>
</tr>
<tr>
<td>Infectious /Infection</td>
<td>94</td>
<td>13%</td>
</tr>
<tr>
<td>Unknown fear</td>
<td>34</td>
<td>5%</td>
</tr>
<tr>
<td>Scarring</td>
<td>28</td>
<td>4%</td>
</tr>
<tr>
<td>Fear of treatment</td>
<td>18</td>
<td>3%</td>
</tr>
<tr>
<td></td>
<td>8</td>
<td>4.2%</td>
</tr>
</tbody>
</table>

Table 4.3: Categories of Expectations (with number of patients)

<table>
<thead>
<tr>
<th>Category</th>
<th>Number of Patients</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reassurance / help and advice</td>
<td>287</td>
<td>42%</td>
</tr>
<tr>
<td>Treatment</td>
<td>273</td>
<td>40%</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>121</td>
<td>18%</td>
</tr>
<tr>
<td>What's behind the condition</td>
<td>74</td>
<td>11%</td>
</tr>
<tr>
<td>A cure</td>
<td>71</td>
<td>10%</td>
</tr>
<tr>
<td>Change in treatment</td>
<td>57</td>
<td>8%</td>
</tr>
<tr>
<td>An examination</td>
<td>51</td>
<td>7%</td>
</tr>
<tr>
<td>Prognosis</td>
<td>12</td>
<td>2%</td>
</tr>
<tr>
<td>Whatever doctor wants</td>
<td>7</td>
<td>1%</td>
</tr>
</tbody>
</table>

98
Table 4.4:
Examples of the written responses of the patients

- It's itchy, persistent and I have not slept properly for months. I also worry what people think? In expectation section she wrote —“cure me please”.

- I will have to stop work if my skin does not get better. I want my normal skin back.

- A 19 year old female attending for mole check up is a good example where fears can be exaggerated in benign conditions, she wrote —“my freckle could be life threatening.”

- My skin condition is embarrassing and I know people will see it.” In the expectation section he wrote —“I need healthy clear skin and that will give me a peace of mind”

- A 16 year old girl with hirsutism wrote —“I have everything wrong with my skin and I am like a hairy ape.” I am fed up with my life because of it and it is depressing me so badly. She was looking for cure for her skin condition.

- A 37 year old female with long history of self-harming leading to marked cutaneous scarring stated —“I want doctor to understand me and not criticise me”.
• A patient diagnosed with delusion of parasitosis wrote —I feel that something is crawling on me and then it bites me. I believe something microscopic is living inside me”.

• A 14 year old boy with history of severe eczema stated —I am not able to swim and wear Rugby shirt as it is very embarrassing when my friends see it. I want my skin to be clear so that I can sleep without itching."

• I feel I am excluded from the society as I am not able to do routine activities like swimming.

• A 12 year old girl with eczema stated —I want my hands, legs and nails to be like other people have”. People laugh at me as no one else has it.
CHAPTER 5

Delusion of Parasitosis - Lessons Learnt
**Introduction**

A delusion of parasitosis (DP) manifests in the patient's firm but incorrect and unshakeable belief that they have skin symptoms due to an infestation with insects. Patients with delusions of parasitosis are not psychotic but have a delusional disorder of a somatic type (American 2000). There is no grossly disorganized behaviour or generalized thought disorder.

DP was first described in 1894 by Thibierge, who named it acarophobia (Thibierge 1894) but in 1946 Wilson and Miller renamed the disorder delusions of parasitosis (Wilson et al 1946). Although in essence, this illness of perception and thinking is essentially a psychiatric disorder; patients usually seek help from their primary care physician and dermatologists.

The pathogenesis of delusions has been theorized for almost a century because of inadequacies of definition and lack of laboratory tests. One possible model for explanation is the vulnerability-stress model, which proposes that an individual has unique biological, psychological and social elements (Ingram et al 1998). These elements include strengths and vulnerabilities for dealing with stress. Research supports the notion that stressful life events may trigger the exacerbation of psychotic symptoms. DP according to this model may be triggered by stress (i.e. scabies). Thus, at the start of complaints, there may be a parasitic infestation and the delusional disorder occurs for the first time according to the vulnerability-stress model.
The DP patients are usually middle-aged to elderly with few social contacts and normal cognitive and social function. Other characteristic profile is an old, multi-morbid patient with dementia, living in a nursing home who gradually develops symptoms of DP (Freudenmann et al 2007). Wilson and Miller reviewed all available cases and added six of their own. They described four different etiologies (toxins, schizophrenia, old-age depression, and paranoia/delusional disorder) but also noted that 8 of the 51 patients (15.9%) had cerebral atherosclerotic or senile disorders (Wilson et al 1946).

Another interesting and indicative feature is the size of the ‘so-called bug’. They are often described as ‘almost too small to see’ (Schwarz et al 2001), such that it is difficult for the patient to catch one. Larger than centimeters creatures are quite uncharacteristic for DP. Patients often believe that most frequent source of infestation is a transmission from other humans, while plants or some part of the patient’s housing as well as animals and pets are less frequently blamed. It must be emphasized that a real infection or infestation can be a trigger for DP.

Typically these creatures are spotted by DP patients ‘inside’ or ‘under’ the skin, while it was ‘in the body, blood or muscle’ in organic brain syndromes and ‘on’ the skin in cases secondary to schizophrenia (Marneros et al 1988).

In many cases, patients believe that family members, friends, and other contacts, as well as personal belongings are also infested (Dunn et al 2007).
Patients then start to examine their skin obsessively. The search gradually becomes more elaborate, and often instruments such as magnifying glasses and tweezers are used to examine the skin further (which in some cases can take many hours every day (Freudenmann et al 2002).

Patients also consult numerous family doctors, dermatologists, microbiologists, and infectious disease specialists. Some patients also seek help from pest control officers and traditional healers. It is not surprising that patients do not seek psychiatric help and refuse psychiatric referral, as they do not believe that they have a psychiatric illness (Freudenmann et al 2007).

Signs of cutaneous disease are lacking apart from multiple excoriations. The physician should not expect patients to be “relieved” by negative findings. Normal cutaneous findings can be interpreted as “incompetence” on the part of the doctor and patients generally look for alternative explanations to maintain their beliefs or tend to change their doctor.

Interestingly, most patients are looking for treatment as they “already know” what they have and often ask to be prescribed the most aggressive “antibug” or other medication to get rid of the pathogens. A prescription of any anti-infective without clear indication is no option and reinforces the delusional belief (Freudenmann et al 2002).
When patients are able to catch some of the pathogens, they are taken to the physician as proof of infestation. These specimens are usually presented in a small bag, piece of paper, or plastic foil to protect it. It is telling that these allegedly dangerous pathogens are handled without disgust or anxiety of becoming infested. Instead, they are collected and stored like trophies (Freudenmann et al 2003). The proofs usually consist of uncritical material, such as dander, crusts, scabs from healing skin lesions, hair, dirt, and sand (Goddard et al 1995, Zomer et al 1998).

Not only do DP patients frequently change bed sheets, mattresses and use several disinfectants for the whole house and the body but they also change their underwear after some hours, even at night (Lyell 1983). Countless over-the-counter disinfectants, soaps, and chemicals are used.

Sometimes, the presence of real skin problems appears to make it more believable that the patient has a real infestation of the skin. Patients may become angry and desperate after failing to get rid of presumed creatures. Extreme actions such as, burning one’s “infested” furniture, other goods, and clothes or even escaping from home have been described in the literature (Goddard et al 1995).

Some patients develop secondary depression within the course of the delusional disorder. Suicidal ideation (Sandoz et al 2008), attempted suicide and committed suicide have also been reported (Monk et al 1994).
Although DP is an illness of perception and thinking is essentially a psychiatric disorder, patients usually seek help from their primary care physician and dermatologists. Patients with delusions of parasitosis usually reject psychiatric referral. By the time the patient presents to the dermatologist or psychiatrist, it is not uncommon they would have been seen by many doctors and specialists. Patients frequently describe cutaneous symptoms of crawling, biting, and stinging sensations as the first evidence of infestation.

Many patients develop hostility to persons who deny their infestations, even to the point of threatening to shoot any physician who denies the existence of the parasites (Lynch 1993). In some cases, patients have killed their pets to rid themselves of the perceived source of the infestation or have spent thousands of dollars to treat their homes with pesticides (Goddard 1994). Patients have even been reported to immolate themselves to rid themselves of their parasites (Monk et al 1994).

Most patients with DP have sought help on websites these days. Specialized Internet websites have become an important communication platform for almost any disease. They can be helpful, but in the case of DP, wrong beliefs about unknown pathogens and uncritical recommendations of hazardous self-cleansing strategies are also spread and shared (Vila-Rodriguez et al 2008).
The clinical course of DP is quite variable from an insidious onset to a chronic course, usually for years. Chronic courses also occur in elderly patients with DP secondary to medical illnesses. In intoxication, the onset of DP is acute and symptoms last only for hours, days, or weeks.

In approximately 5-15 % of patients, delusion of infestation is shared by another person, usually a close relative or spouse. This phenomenon is known as folie à deux (French for "craziness for two") (Wykoff 1987).

It is the aim of the first visit to rule out true infections and any other organic or toxic cause, as well as the effect of prescribed medication. Later visits start with highlighting the patient's suffering while pointing out that something can be done. The first measure is to rule out a true infestation. This includes some basic laboratory and a full skin examination with skin scrapings and possibly skin biopsies where indicated. This is the most important step because a real infestation must be excluded (Wykoff et al 1987).

Additional history taking and further investigations are usually needed at this stage to rule out other causes of pruritus and psychiatric symptoms. The physician should express interest in the patient's beliefs and promise a thorough evaluation of the case.

Explaining the diagnosis is the most crucial part of the therapy. The dermatologist should spend some time explaining that there is the possibility of
infestations that cannot be identified at present but that everything possible test will be done to test to find out the species. The dermatologist might indicate that there is also a second possibility, of an —oversensitivity and over-activity in the central nervous systems,” which can be the cause for creeping, crawling, and itching.

It is also the prime importance to win the patient's trust, by means of thorough examination, appropriate investigations and a good explanation of the symptoms. The physician might introduce the idea that a trial of —euroleptics” seems promising and reasonable.

If patients have become wary, however, it will be literally impossible to convince any patient, even for a skilled psychiatrist. Some authors have used psychotherapy, with or without confrontational denial. It is helpful in 10% of cases, at best (Wykoff et al 1987).

Pimozide was the first antipsychotic drug that was broadly used to treat DP (Hamann et al 1982). Pimozide has a dopaminergic effect and blocks opioid receptors. It should be started at a dose of 0.5 - 1 mg daily. The dosage of pimozide can be slowly increased by 1 mg increment every week until the patient experiences improvement or unacceptable adverse effects occur. Clinical improvement is often evident with dosages in the range of 2-4 mg/day.
The *newer neuroleptics* are the emerging treatment of DP and are associated with a lower risk of extrapyramidal effects.

Risperidone, an atypical antipsychotic that acts on serotonergic 5-HT2 and dopaminergic D2 receptors, has a much better safety profile than pimozide. Risperidone has been reported to be effective in the treatment of DP (Elmer et al 2000).

Sulpiride is an atypical antipsychotic drug used mainly in the treatment of psychosis associated with schizophrenia and major depressive disorder and there are case reports of its use in DP (Takahashi T et al 2003).

Other atypical neuroleptics are olanzapine, which can cause sedation, anticholinergic effects and weight gain (Meehan et al 2006). The benefits and risks of newer antipsychotics in the treatment of DP need to be further evaluated.
Aim

We were keen to review and learn from our DP patients because we were conscious of the significant morbidity of this condition and also the therapeutic difficulties it presents to the dermatologist trying to help the patient to accept psychiatric drug treatment. We were interested in understanding the impact of this disease on their daily life. We reassessed our patients with DP to see what lessons we could learn from them.
Methods

In this retrospective study, 14 patients were diagnosed with DP seen between 1995 and 2008. The diagnosis was made on detailed history and clinical findings.

All patients were under the care of one consultant dermatologist (BR) and were seen at 4–6 month interval in the dermatology outpatient department. The patient's records were retrieved by our departmental database. The study was approved by local ethics committee of Midwestern Regional Hospitals, Limerick.

The following data were collected: age, sex, date of diagnosis, age at diagnosis, duration of symptoms, marital status, partner affected, employment history, previous psychiatric illness, previous parasitic infection, treatment, response to treatment, course and outcome of the disease.

We also gathered the written and verbal testimony used by patients to describe their symptoms during the consultation. Further reassessment was made by telephone contact with the patients and their family doctors.

The response to treatment was categorized as complete remission (CR), partial remission (PR) or no response (NR).
Results

14 patients, 7 male and 7 female, were identified with mean age of 45.5 years (24-74) (Table 5.1). All patients were Caucasian. Five patients were married, 2 separated and 7 were single. All were employed. Mean age at presentation was 41 years (22 - 68) and mean duration of symptoms at first consultation was 44.5 months (3 -155). Mean duration of follow up was 50.1 months.

Four patients had consulted other dermatologists before attending us. Folie á deux occurred in two couples.

Proof of the infestation, such as "specimens" delivered in a matchbox, were provided by 3 patients. Case 5 lined the match box with black tape which was done to enable the doctor to 'see' the parasites more clearly. The interior appearance of this match box looked like a 'coffin'. On inspection, these were not parasites (Figure 5.1).

One patient was so deluded with this condition that he stopped travelling on a bus and also made himself socially isolated, as he did not want his parasites to be transferred to general public.

Three patients had their symptoms for more than 9 years (cases 2, 6 & 7). Although they were troubled with daily symptoms, all three acknowledged the intensity of their DP symptoms had diminished over the years. They described the parasite as black or brown colour living on or just beneath the skin. Two
patients had clear visual component to their symptoms. Case 8 described the parasites as hovering just above his skin.

Case 3 observed the parasite just above his skin, head (Figure 5.2) as well as penetrating through an external fixation wound on his arm which he sustained after an accident i.e. a visual component to his delusion (Figure 5.4). Although most patients mentioned a crawling sensation within their skin, two patients described that “insects ran through their skin”.

Table 5.2 shows the clear language used by our patients to describe their distressing symptoms.

The symptoms were very intrusive for patients. Case 5 described having to stop his hobby of motor-rally cycling, as he could not concentrate while driving his bike. The strong symptoms of biting and crawling in his scalp impaired his ability to concentrate while motor cycling.

Seven patients had a history of previous scabies infection, diagnosed and treated by their family doctors. There was no possible way of confirming whether or not these patients had scabies. Although, the distressing “crawling sensation within the skin” was graphically described by all 14 patients, we initially mistakenly diagnosed two patients as scabies and one as neurotic excoriations.
Five patients had previously attended psychiatrists with depression but this was not a current diagnosis in any of them. Two patients had secondary associated conditions (case 8 had concurrent recreational drug use with cocaine and case 10 had Alzheimer’s disease). Although excoriations, erythema and lichenification were observed in six patients, eight patients had no skin abnormalities.

**Antipsychotic treatment**

Twelve patients were treated with antipsychotic drugs: nine were treated with pimozide and of these, only two cleared completely (case 1 & 6). One was able to come off pimozide and one remains on it. The non-responders had to discontinue because of dose-related extra-pyramidal side effects.

Four were treated with sulpiride with one (case 5) reported improvement. Four patients had risperidone and none of them reported clearance of symptoms. Patient 11 was given gabapentin (anti-epileptic drug) resulting in improvement of his symptoms.

Nine patients were seen in the last 6 months with five still having active DP symptoms. Four were lost to follow up. The consultation with a DP patient is challenging because a number of factors may be involved. Table 5.2 lists some of these factors that we noticed in the consultations.
Patient 14 had very severe symptoms. He had spent over €1400 Euros on two different pesticide companies. He set up a website dedicated his condition with numerous photographs of the ‘insects’ as well as video footage. He had become socially very isolated and was avoiding attending hospital for other unrelated medical conditions in case he ‘would pass on’ his condition to others. Prior to attendance he acknowledged active suicidal ideation.

Because his symptoms were so severe coupled with threat of suicide it was decided, after advice from Liaison psychiatry, to use intramuscular risperidone, which was administered in the Dermatology outpatients on a fortnightly basis.

This resulted in a dramatic reduction (50%) of symptoms after 2 treatments. He reported being able to sleep properly for the first time in 10 months. Because the patient felt so much better, rapport and concordance was established and the improvement has been maintained to date.
Discussion

_Cutaneous findings_ in DP range from none at all to excoriations, lichenification, and ulcerations, all of which are factitious in origin resulting from the patient's efforts to dig out "the parasites." The diagnosis of DP is usually made on the basis of the clinical history alone, but it is important to do a careful skin examination to rule out underlying systemic disorder such as scabies, insect bite reactions, chronic folliculitis and dermatitis herpetiformis. We misdiagnosed DP in three patients mistaking itch and physical signs for organic disease.

Patients often bring in “_specimens_” in a small container, which are actually pieces of skin / hair or may identify —_bugs_” during examination by probing into skin. This behaviour is very characteristic and has been referred to as "the matchbox sign" (Lyell 1983).

In our series, three patients brought in the proof of the infestation, in a matchbox. Case 5 was pleased to have captured some of the parasites which tormented him and entombed them in the dark coffin he made out of a match box. In our series, Folie á deux occurred in two couples.

DP must be distinguished from _formication_, which is the sensation of crawling, biting, and stinging on the skin. Patients with only formication are not delusional; they are not fixed on the idea that their cutaneous sensations
are caused by parasites. They can accept the evidence that they do not have an infestation.

Certain drugs such as cocaine and amphetamines can induce formication and, sometimes, a delusional state clinically identical to that of idiopathic DP. The induction of formication with cocaine is well known among the users and has been labelled "cocaine bugs." (Siegel 1978, Mitchell 1991). It has been related to the development of a paranoid psychosis, similar to acute paranoid schizophrenia (Brady 1991). The treatment for the drug-induced DP is difficult, unless the patient is detoxified with respect to the drug of abuse. The antipsychotic medication, pimozide, which is the traditional treatment of choice for DP can work for patients with only formication and who are not delusional.

DP is an isolated symptom complex. Most of our patients appeared to function normally. The isolated symptomatic nature of this condition is illustrated in that we had previously seen case 3 in his capacity as the main caregiver for his son with atopic dermatitis. He was to all respects entirely normal until he attended us as a patient and began to explain his DP symptoms.

Patients with DP can have hallucinatory experiences that are compatible with the delusion, which may be accompanied by illusional misperceptions. Two of our patients had visual components to their delusion. Case 3 was totally
convincing that the parasites had entered through the surgical wound on his forearm.

When evaluating a patient who may have DP, it is important to make sure that there is no other psychopathology besides the fixed belief and that the delusion is not secondary to another mental or physical illness. For example, some schizophrenic patients may believe that they are being infested by insects as a manifestation of their paranoid delusion.

There are many different organic psychosis that can mimic DP, including drug abuse, dementia, malignancies, cerebrovascular disease, and vitamin B12 deficiency. Johnson et al have extensively reviewed medical disorders associated with apparent DP (Johnson et al 1985).

It is difficult to know what percentage of patients will accept neuroleptic medication. The Reilly and Batchelor survey reported that 60% of patients will accept the neuroleptics, and of these patients, two-thirds will benefit. There is no evidence suggesting that persons who experience parasitic delusions go on to develop a generalized psychosis (Reilly et al 1986).

The treatment of DP is difficult as these patients may be otherwise well but have a fixed unshakeable belief that they are infested. Even though it is a delusional disorder, these patients usually present to a dermatologist, because they are convinced they have a dermatologic problem. The condition may be
intractable partly because the exact neurochemical cause is not known and although patients have no obvious cognitive impairment, it may be associated with other psychiatric conditions. Patients with DP almost always reject the diagnosis and psychiatric referral.

An empathic approach is required, acknowledging the reality of patients’ symptoms without challenging or confirming their views about the cause. The successful treatment of DP requires an establishment of trust with the patient. Case 8 broke down into tears of relief when we acknowledged what he was going through by saying —as must be simply awful for you".

He then said that he had been afraid that we might be like all the other doctors” who thought it was —all in his head”. Simply acknowledging the misery of his symptoms opened the therapeutic window and encouraged him to take pimozide successfully. Patients did seem to appreciate the chance to express the distressing nature of their symptoms (Table 5.2) and a supportive approach allowed a therapeutic relationship to develop.

Initiation of treatment is particularly difficult. We tried to encourage patients to take neuroleptic medicine partly by explaining that these drugs can have more than one therapeutic action and they particularly target the biting and crawling sensations within the skin. This is partly because patients want an explanation as what infestation they have. The consultation is difficult because the doctor is trying to encourage patients to take appropriate anti-delusional medication
which may not seem rational to them. A further complication in the follow up consultation is if the patients have used the Internet for help in their condition. This can lead to further confusion for the patient.

Trying to push the dosage of pimozide beyond the 4-6 mg/day range may increase the risk of extrapyramidal adverse effects such as drug-induced parkinsonism, akathisia, dystonia, and potentially irreversible tardive dyskinesia. Pimozide also has the potential for cardiac toxicity by prolonging the QT interval and causing ventricular arrhythmia. A meta-analysis of 1223 case reports demonstrated a full remission rate of 50% with pimozide treatment, compared with a 30% remission rate in patients treated before pimozide was used (Trabert 1995).

In our series, two of the five patients started on risperidone had partial response. A limited number of case reports have documented the effectiveness of sulpiride in the treatment of DP and two of our patient’s symptoms are partially controlled on it (Takahashi et al 2003). We were surprised by the persistence of symptoms and poor response to pimozide and risperidone in our patients. In our series, side effects of neuroleptics limited treatment efficacy in spite of initiating therapy at low dosage to minimise toxicity. Factors contributing to poor prognosis in our group included prolonged DP symptoms before referral and past history of depression (5 out of 14).
A recent systematic review of the effectiveness of typical and atypical antipsychotics in primary DP by Lepping et al concluded that, in the absence of controlled trials, there is limited evidence that antipsychotics are effective in primary DP (Lepping et al 2007).

The response to intramuscular risperidone in our patient (no. 14) opens the possibility that better concordance can be achieved over oral neuroleptic administration.

Patients are quick to change doctor if they sense that their belief is not shared by the doctor and, due to lack of insight, patients are usually very resistant to the idea of psychiatric assessment. Supportive psychotherapy is a good adjunct to somatic treatment as these patients lack insight into illness. This liaison may be very important as our series shows that DP can be a chronic disorder which may persist for many years.

A treatment guide focused on whether the belief is likely shakeable or fixed offers a graded therapeutic approach starting with benzodiazepine to modern antidepressants (Zanol et al 1998). Use of screening tools like the HADS (Hospital Anxiety Depression Scale) may help clarify if there is an associated underlying depression (Zigmond et al 1983).

A recent paper (Bewley et al 2010) suggested a few key points in dealing with DP patients which are summarised as follows:
Do's and don'ts

Do's

- Take time; take a careful history, including trips to tropical resorts.
- Perform the diagnostic investigations needed (even if you are sure that the patient has no infection).
- Examine all specimens carefully.
- Acknowledge the patient's suffering. Show empathy and offer to help to reduce distress!
- Paraphrase the symptoms ("you are itching," —the sensations," —he crawling," etc.) instead of reinforcing or questioning them.
- Indicate that you are familiar with the problem and that you were able to help other patients not instantly, but after a while.
- Answer that you did not find any pathogens so far, but you are sure that the patient really suffers from his perceptions.
- Try to introduce antipsychotics as the only substances helpful against these processes, as suggested by current research.
- Introduce antipsychotics as helpful against the patient's distress and itching (antihistaminic component of many antipsychotics).
Don’ts

- Do not try to convince the patient or question the patient’s beliefs.
- Do not attempt immediate psychiatric referral or try to establish psychopharmacological therapy too soon.
- Do not use words like —delusional,” —psychotic,” —psychological,” —psychiatric,” etc. (too early).
- Do not use phrases like —calm down” (be happy it’s not infectious,” —it’s only psychogenic,” etc.); this will upset the patient.
- Do not simply prescribe an antipsychotic because different approaches are needed according to the type of DP.
- Do not prescribe antibiotics or any other anti-infective without a real infection (further reinforcing the delusion).
- Do not overlook frank aggression against other health care professionals.
- Do not forget to ask patients with despair and signs of manifest depression about suicidal ideation and to evaluate any risk to others.
Limitation of the study

We would like to acknowledge drawbacks in our report. The findings are retrospective as this is a rare disorder and doing a prospective study would be difficult. The diagnosis of DP was made by a single dermatologist without a structured interview or clinical psychiatric interview. However, the patients were encouraged to see a psychiatric consultant for evaluation, which was declined by most of patients.

Lastly, in our experience in treating patients with DP, we have noted interesting observations, which are listed below from patient's and doctor's point of view.

Patient's point of view

- **Doctor is “blind”:** The patient gives us the "proof" in a matchbox but the doctor still cannot cure them.

- **Doctor is “fatigued”:** Confused by repeated visits to different doctors, different diagnoses, but no treatment works.

- Internet confusion: Unfiltered advice much of which can be erroneous e.g. pseudo diagnoses (Morgellon's disease).

- **Doctor is “confused”:** Some patients learn that the doctor’s diagnosis is DP and then a game ensues where they try to understand why the doctor’s confused. —“You think I am imagining this doctor”.

- **Condition fatigue:** DP can be very chronic. This must be very frustrating for the DP patient.
Doctor’s point of view

- **DP is partly a diagnosis of exclusion:** The doctor has to exclude organic disease (scabies/ cocaine use/ dementia).

- Misdiagnose: It is easy to misdiagnose DP as there may be minimal signs which if present may be non-specific.

- **The First “Fish out of water” scenario:** Most dermatology patients are not deluded. Therefore we have unfamiliarity with helping deluded patient.

- The Second —Fish out of water**: Dermatologists use a range of drugs that they know well. They don’t use the drugs required in DP daily and therefore have difficulty using them effectively.

- Folie a deux: Both the patient and their partner may be affected meaning there is no intermediary that the dermatologist can work with to encourage treatment concordance.

Sources of resolving conflict in the consultation with the DP patient:

This first requirement is for the dermatologist to acknowledge that these patients are the ones suffering with their condition and that they present to us – and not to the psychiatry - so we have a duty of care toward them. We have insight and they do not. They present with a perceived problem of their skin and the onus is on the dermatologist to try and help them.
**Patient's point of view; explained**

The doctor is blind: Let us examine their skin and the matchbox with care.

Doctor fatigue: Acknowledge that it, the condition, must have been and is very difficult for them to live with. In that we neither collude nor dispel. We just acknowledge the hard time they have put in with the condition – This worked for the young cocaine user patient 8.

Internet confusion: advice to encourage the patient away from Internet explanations (typing delusion of parasitosis and treatment in Google search engine can cause confusion) as a lot of it is financially driven and unhelpful for DP patients.

The doctor is confused: “You think I am imagining this doctor” …I think the honest approach is to gently and firmly demure. “—know the symptoms you have are very real and we want to help you”.

Condition fatigue: Getting patients to write down their fears/concerns is not dismissing them and helps acknowledge that their experience is real, valid and challenging.

**Doctor's point of view: explained**

DP is partly a Diagnosis of exclusion: exclude organic disease ... and once you do reassure that –tests x, y and z are clear …but this set of symptoms that you
have are difficult to pin down; there is no diagnostic test for it yet but we are going to keep working on your behalf”.

**Misdiagnose:** Don't be too hard on ourselves – it is easy to misdiagnose.

**The First “Fish out of water”:** the deluded patient – here we need help from liaison psychiatry …build up skills by collaboration remembering the patients come to us *out of preference* and just like we have learned surgical skills to enable us operate, these are skills we can learn.

**The Second “Fish out of water”:** Much as answers for first “fish out of water” above – consider a once monthly mini psychocutaneous clinic.

Focusing on a clinical area allows the dermatologist to develop skills better for that condition. We do that for many specialised areas within dermatology such as Laser, biologic therapies, severe psoriasis so these psychocutaneous consultation skills can be developed.

**Folie a deux:** This is especially difficult. Getting concordance may require Liaison psychiatry help.

We have to *turn toward what is in front of us* – the DP patient. We are the only doctors with sufficient skills to exclude other dermatoses and the patient has come to us for help.
Conclusions

In summary, we present a series of 14 patients with DP. We initially misdiagnosed two patients. These patients were very distressed by their condition as they described their symptoms in graphic language.

These patients needed help as they might otherwise become orphaned or lost between the two specialties of psychiatry and dermatology. While, we have the skills to make a diagnosis, dermatologists are not experienced in guiding a delusional patient to take oral neuroleptic medicine nor have we enough daily experience of maximising the therapeutic effects and minimising the toxicity of neuroleptic drugs.

Our series therefore, underscores the need for liaison psychiatry service within the dermatology outpatients. This would allow the DP patients to have a consultant psychiatrist opinion in collaboration with the dermatologist in a non-psychiatric setting. Such liaison is important to clarify whether there is an underlying psychiatric depressive illness and to optimise the therapeutic approach with modern neuroleptic drugs.

If liaison psychiatry service is not available or rejected by the patient, awareness of modern antipsychotic drugs with their lower side effect profile may enable the dermatologist to initiate therapy successfully. It is likely we will see more DP patients as associated conditions are increasing with rising
recreational drug use, aging and Alzheimer’s disease. Our study has also shown the impact of this disease on patient's quality of life.

Finally, closer working relationships between dermatologists and mental health professionals will help to address the psychological needs of patients and their families. I have tried to contribute to some of these issues in my thesis.
<table>
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<th>Case no</th>
<th>Sex / age</th>
<th>Marital Status</th>
<th>Age at Presentation</th>
<th>Duration of symptoms at first presentation</th>
<th>Partner affected</th>
<th>Previous parasitic infection</th>
<th>Back ground psychiatric history</th>
<th>Treatment</th>
<th>Outcome</th>
<th>Lost to follow up</th>
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<td>off pimozide and lost to follow-up</td>
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<td>Pimozide</td>
<td>PR and on sulpiride</td>
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<tr>
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<td>No</td>
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<tr>
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<td>4 months</td>
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<td>No</td>
<td>No</td>
<td>Risperidone</td>
<td>No record of response and lost to follow-up</td>
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<td>57</td>
<td>12 months</td>
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<td>No</td>
<td>Yes</td>
<td>Risperidone</td>
<td>PR and still On risperidone</td>
<td>No</td>
</tr>
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</table>

[Partial Remission (PR), No Response (NR), Complete Response (CR)].
Table 5.2

What is like to live with delusional parasitosis? These words were used by our patients to describe their symptoms:

- It is like bugs crawling all over me.
- A virus is running inside me, irritating and biting all over my skin.
- Parasites entered into my skin (through an external fixation wound).
- Insects entered into my skin through a wound and they crawl on me.
- I fear that I can pass these bugs to my partner.
- I feel like a virus is biting me and I cannot sleep.
- My biggest fear is that I am contagious.
- Itchy mites drive me mad. I use ice-cubes in my stockings to relieve the itch.
- Insects are crawling beneath the skin disturbing my sleep.
- It feels like bugs all over my body just eating me.
- My skin feels dirty. I see black things on my skin.
Legends for figures

Figure 5.1: The Match box sign (Coffin sign); one patient lined the match box with black tape to enable the medical staff ‘see’ the ‘parasites’ easier

Figure 5.2: Patient using his hands to illustrate the crawling sensation. Patient gave written permission for his facial pictures to include in this thesis
Figure 5.3: External fixation wounds of patient in figure 5.1.

The patient attributed these wounds to be the entry points of his infestation
Chapter 6

Exploring the role of the clinical psychologist in Dermatology clinic
Introduction

The skin is the largest organ in the body – the key organ of communication, sexual attraction, physical activities and immediate visibility. When the skin is damaged there is significant impact on the sufferer - particularly in loss of function in these four realms of communication, attraction, physical activities and visibility.

Dermatologists are aware that all patients with dermatoses can be affected by adverse psychological impact because of their skin conditions. In addition, there are conditions that are primarily psychological but present to us as the patient's perception is that their problem is cutaneous – examples would include delusional parasitosis (DP) and Body Dysmorphic Disorder (BDD). To the sufferers with BDD they misperceive a problem with their skin and it is our role to offer them appropriate care.

There are significant consequences from undiagnosed or untreated psychological morbidity associated with skin conditions including depression/chronic anxiety and suicide. We may be unaware of the suffering engendered by severe dermatoses.

Dermatologists are not trained to intervene appropriately in these patients. Dermatologic training focuses mainly on those with ‘organic diseases’. There may be no therapeutic space for the patient in these situations. Dermatologists may get frustrated and resentful that such patients present to them. It may lead
them to deliberately ignore that there is a significant psychological component in the consultation. This behaviour may arise from the doctor’s previous experience that managing such patients is time consuming, and challenging.

Conversely – engaging with this part of our work means that no one is excluded from care. We learn to meet whatever condition the patient presents with. We see whether we can define with the patient the problems that need addressing. The patient and their needs are at the centre of the contact and the doctor benefits by not ignoring the transaction and how it affects them as a carer.

While studying our patient’s dermatologic fears, the atopic eczema group and those with DP it became clear it would be helpful to have a professional opinion from a different psychological perspective.

This was because we had become:

- Aware that there is ‘something else going on’ that the traditional medical consultation was not addressing or perhaps not able to address.
- Aware of background busy clinic and noise – which precluded patients speaking openly.
- Aware that by not addressing this ‘something else’ or the unexplored area(s) of the consultation we were failing the patient.
Aware that people can be helped by psychologists to ‘see’ things as they are and perhaps re-frame how they see things. This could allow them to move forward.

Aware that sometimes the patient is burdened with severe or very chronic organic disease and that they may need assistance in coping with it.

Clinical psychology aims to reduce psychological distress and to enhance and promote psychological well-being. A wide range of psychological difficulties may be dealt with, including anxiety, depression, relationship problems, learning disabilities, child and family problems, and serious mental illness.

One of the first roles of a clinical psychologist in a counselling setting is to assess and diagnose the patient. Part of this process involves actively listening to what the patient is saying as well as discerning the true goals.

To assess a patient, a clinical psychologist may undertake a clinical assessment using a variety of methods including psychometric tests, interviews and direct observation of behaviour. Assessment may lead to therapy, counselling or advice.

Intervention through counselling is part of the clinical psychologist’s role. Intervention work typically happens once there has been an assessment of the
patient's true needs. Interventions are usually based on specific techniques such as cognitive behavioural therapy.

Cognitive behavioral therapy is a psychotherapeutic approach that addresses dysfunctional emotions, maladaptive behaviors and cognitive processes and contents through a number of goal-oriented, explicit systematic procedures (Schacter et al 2010).

If the psychologist suspects there are serious undiagnosed mental disorders in existence, they may recommend a formal psychiatric assessment. The effective management of skin disorders involves consideration of associated emotional disorders in dermatology patients.

In cases, when psychotherapy is not possible, for example for social and cultural reasons, the well-informed dermatologist should be able to listen and show empathy, and eventually to prescribe antidepressant medications. The general practitioner is then the best co-worker if the dermatologist cannot follow the patient over a long time.

It has been observed by dermatologists that psychiatric disorders are frequent among patients with skin problems and are more frequent than in the general population. The skin has a special place in psychiatry with its responsiveness to emotional stimuli and its ability to express emotions such as anger, fear,
shame, and frustration, and by providing self-image and self-esteem. (Koblenzer, 1983).

In this chapter, we evaluate the psychosocial distress shown by some of our patients and the need for psychotherapeutic interventions within the framework of the clinical psychologist liaison service during the period.

Contact with the Department of Psychiatry had yielded the support of Dr E'OD, a Clinical Psychologist, (CP) who was assigned to the Dermatology Clinic for two sessions a month. This component of the thesis is based on studying the first 10 patients referred into this service.
Methods

The study was conducted from January 2007 to July 2008 in the Dermatology Department at the Mid-Western Regional Hospital, Limerick. The first ten patients who were referred to a clinical psychologist were included in this study.

All the referred patients had a primary skin disease diagnosis which was significantly impacting on their quality of life. Data collected included the reasons for referral to the Clinical Psychologist; dermatological diseases associated with psychosomatic factors (e.g. Atopic dermatitis, psoriasis, compulsive skin picking) or diseases that are based on a psychiatric disorder (dermatitis artefacta) and lastly if they had psychiatric disorders secondary to social isolation or stigmatization (depression comorbid with diseases such as psoriasis or atopic dermatitis).

A detailed assessment was conducted by the clinical psychologist (E O'D) by patient interview. The setting used by the psychologist was physically different to the normal clinic – more comfortable chairs were used. There was a signage to prevent interruptions to the consultation while the patients attend the psychologist. The psychology session was run in tandem with the outpatients. It was part of the service.
Questionnaires

The table 6.1 shows all the scales used in the 10 patients.

A self-assessment of the QOL Questionnaire ‘Patient Satisfaction Survey proforma’ (Table 6.2) was used after patients had completed the sessions with the clinical psychologist. Quality of life was assessed by calculating an index showing how skin symptoms affect the patient’s everyday functions by means of the DLQI (Finlay et al 1994).

Dermatology Life Quality Index (DLQI)

The Dermatology Life Quality Index (DLQI) was developed in 1994 (Finlay et al 1994) and today is the most commonly used dermatology-specific QOL measure in clinical trials of skin diseases (Both et al 2007, Le Cleach et al 2008).

The DLQI has been used in more than 36 skin diseases (inflammatory, non-inflammatory and skin cancers) in more than 32 countries and is available in more than 55 international language versions (Basra et al 2008). The DLQI has been shown to be easy to use in clinical practice because of its simplicity, (Bronsard et al 2010) with an average completion time of approximately 2 minutes (Loo et al 2003).
It consists of 10 questions concerning dermatologic patients’ perception of the impact of skin diseases on different aspects of their QOL over the last week. The items of the DLQI encompass aspects such as symptoms and feelings, daily activities, leisure, work or school, personal relationships, and the side effects of treatment.

Each item is scored on a 4-point scale: not at all/not relevant, a little, a lot, and very much. Scores of individual items (0–3) are added to yield a total score (0–30); higher scores mean greater impairment of a patient’s QOL. A formal approval to use DQoL questionnaire in our study was taken from the Authors.

Current psychological symptoms were assessed using the SCL-90R checklist (Derogatis 1976), a self-rating test that requires the patient to indicate how much he/she is distressed by each of 90 possible symptoms. SCL 90R is a broad based assessment of current psychological symptoms across a range of different mental health disorders, such as anxiety, depression, obsessive compulsive disorder and somatic disorders.

The Minnesota Multiphasic Personality Inventory (MMPI), a measure of person’s perception and preoccupation with their health and health issues, was also used for personality tests to assist in identifying personality structure and psychopathology (McKinley 1944, Butcher 1990).
Beck Youth Inventories contains five inventories with each contain 20 questions about thoughts, feelings, and behaviours associated with emotional and social impairment in youth. Children and adolescents describe how frequently the statement has been true for them during the past two weeks, including today. The inventories can be administered individually or in a group (Hodges KK 1985).
Results

Ten patients (2 male: 8 females) with a mean age of 38.5 years (range 17-74 years) were included. Dermatological diagnosis for 10 patients was as follows; compulsive skin picking (4), psoriasis (2), atopic dermatitis (2), Hidradenitis suppurativa (2).

There was a mean of 4.4 sessions per patient. One patient (case 1) did not find the CP intervention helpful and six patients found it “very helpful” in the feedback questionnaire. Table 6.3 provides basic data and outcome of the sessions in the group for all 10 patients.

The following are the case histories of all 10 patients and it includes: primary skin disease, reason for referral, the clinical psychologist's assessment and intervention, outcome, and results of the feedback questionnaire.
Case histories (of 10 patients)

Patient 1: (Atopic dermatitis AD)

A 17 year old male patient had atopic dermatitis (AD) since early childhood which had gradually worsened in the previous two years. Comprehensive topical atopic dermatitis treatment did not seem to be working. During the consultation, he appeared very quiet and shy and was always accompanied by his mother. She later revealed that his other brother age 20 had died recently. Because of a lack of improvement with conventional therapy, a concern regarding concordance and long period of grieving, he was referred to the clinical psychologist (CP).

Clinical Psychologist evaluation

During the session, he mentioned his father had died 10 years earlier; he was sad at the time, following this death, but was able to get on with life. He revealed that he was under enormous stress following the suicide of his brother in 2006 at the age of 20 years and he missed him a lot.

Although his AD, was severe in his childhood, he felt it was not impacting on his life very much. In the session it was evident that he used the treatment intermittently and was open to looking at ways to help him form a routine that would offer a better compliance. He appeared to have a poorly established routine in relation to his use of the treatment. He was not clinically depressed. After the session, in the questionnaire, he found the session was helpful.
—somewhat”. He also felt that his skin had improved very much. He was not very keen to have further sessions with the CP.

**Patient 1: Satisfaction Questionnaire**

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<tr>
<td>1. Benefit from CP session</td>
<td>not helpful</td>
</tr>
<tr>
<td>2. Improvement in QoL:</td>
<td>Somewhat</td>
</tr>
<tr>
<td>3. Improvement in skin condition: very much</td>
<td>very much</td>
</tr>
<tr>
<td>4. DLQI before the session:</td>
<td>6</td>
</tr>
<tr>
<td>5. DLQI after the session</td>
<td>0</td>
</tr>
</tbody>
</table>

**Patient 2: Compulsive skin picking (CSP)**

A 74 year old female had generalised itch for several years and had no benefit with antihistamines and oral steroids taken in the past. She admitted scratching with different objects resulting in scarring on her arms. She also mentioned being under lot of stress over the last few years, particularly following the death of her sister, which made her skin condition worse. She was diagnosed as having *compulsive skin picking (CSP)*. She deferred the recommended oral treatment. She was later referred to CP for evaluation.

**Clinical Psychologist evaluation**

Through assessment it was apparent that she was continued to grieve for the death of her sister from two years prior. It was evident that she had been
emotionally very close to her sister and they lived next door to one other. Her death was sudden and unexpected and this significant loss had taken its toll on her mental health.

As part of the assessment, she completed the symptom checklist 90R. This assessment was a broad based assessment across a range of psychological disorders. Her scores on this assessment were in the mild to moderate range in relation to depression and hostility consistent with moving through a difficult grief.

She had 4 sessions of cognitive behaviour therapy and made some gains in relation to re-establishing relationships that were lost over the previous two years and began to re-energise in activities within the local community. She reported reduction in her symptoms.

**Patient 2: Satisfaction Questionnaire**

<table>
<thead>
<tr>
<th>1. Benefit from CP session</th>
<th>very helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Improvement in QoL:</td>
<td>very much</td>
</tr>
<tr>
<td>3. Improvement in skin condition: very much</td>
<td>very much</td>
</tr>
<tr>
<td>4. DLQI before the session:</td>
<td>9</td>
</tr>
<tr>
<td>5. DLQI after the session</td>
<td>0</td>
</tr>
</tbody>
</table>
Patient 3: Compulsive skin picking (CSP)

A 40 year old female patient was suffering from 'itchy' skin since 1993. It became evident during the dermatology consultation that she picked her skin because she had a combination of quite severe active linear inflammatory scars on the forehead and older paler scars on her cheeks. She dated her scarring to when she was 23, following a break up of a four-year relationship with her boyfriend. She was diagnosed as a form of CSP in response to stress which was leaving significant scarring on her face. She was referred to the CP.

Clinical Psychologist evaluation

She had good insight into her difficulties and saw clearly the association between increased frequency of picking behaviour and increased levels of depressions and anxiety. Symptom Checklist 90-R (SCL-90-R) indicated that she had a range of symptoms which were included within an anxiety disorder (Derogatis 1976).

During the sessions, she completed relaxation training and had put this to good use. She also had taken part in habit reversal interventions and these helped significantly reduce the frequency of picking behaviour.

She used the sessions to look at some of the other issues in her life relating to her relationships, her integration into the local community and also looked at the possibility of taking up employment outside the home. In each of these
areas she had made significant progress in relation to achieving her goals. In her sessions, a cognitive behavioural approach was used, which she had found helpful and she also had put in place some *distraction techniques* that help her to reduce the picking behaviour.

She reported a significant reduction in relation to her picking behaviour. However, it was evident that on occasion, while the frequency had been significantly reduced, there was occasion that she continued to pick resulting in new wounds.

**Patient 3: Satisfaction Questionnaire**

<table>
<thead>
<tr>
<th>1. Benefit from CP session</th>
<th>very helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Improvement in QoL:</td>
<td>very much</td>
</tr>
<tr>
<td>3. Improvement in skin condition: very much</td>
<td>some improvement</td>
</tr>
<tr>
<td>4. DLQI before the session:</td>
<td>8</td>
</tr>
<tr>
<td>5. DLQI after the session</td>
<td>2</td>
</tr>
</tbody>
</table>

**Patient 4: Psoriasis**

A 66 year old male patient had a history of severe psoriasis for the previous 35 years. His psoriasis was unresponsive to topical agents, phototherapy and systemic agents and he required both methotrexate and biologic agents to control it. It was felt during multiple consultations that he was quite lonely and
depressed even though his psoriasis was responding well to the treatment. He was referred to the CP.

**Clinical Psychologist evaluation**

This patient was living alone and both his parents were deceased. He appeared to have poor social contacts and had a limited circle of friends. He described himself as an anxious man, having a history of panic attacks dating back to the previous six years. It was evident also, that his mood was low at times and he had a number of regrets in his life.

His regrets were in relation to not finding a life partner. However, on questioning, in relation to actions that might need to be taken to help him develop a relationship, he was reluctant to look at these in any positive manner. He reported a number of beliefs which were not based on rational thinking, which included one where he felt that he may pass on his skin condition to other people if he got close to somebody: “Nobody would want to live with me, with this skin condition”.

From time to time he was troubled by ruminations and obsessive thinking, which were often of a sexual nature and he found this very difficult at times. At his final session, he felt that he would prefer to leave things as they were at the moment and did not want further sessions with the CP.
**Patient 4: Satisfaction Questionnaire**

<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Benefit from CP session</td>
<td>very helpful</td>
</tr>
<tr>
<td>2. Improvement in QoL:</td>
<td>very much</td>
</tr>
<tr>
<td>3. Improvement in skin condition: very much</td>
<td>very much</td>
</tr>
<tr>
<td>4. DLQI before the session:</td>
<td>8</td>
</tr>
<tr>
<td>5. DLQI after the session</td>
<td>2</td>
</tr>
</tbody>
</table>

**Patient 5: Hidradenitis Suppurativa (HS)**

A 54 year old female had a 15 years history of a very severe inflammatory skin condition, *hidradenitis suppurativa* (HS), where patients get severe abscess-like lesions in the flexural and groin areas (Von der Werth et al 2001). She required biologic treatment with infliximab to control her severe condition. Over the previous two years, she felt very depressed and was taking antidepressants. She was referred to the CP service mainly for evaluation as it was clear she had found her skin condition hard to live with.

**Clinical Psychologist evaluation**

This patient was under considerable stress and was *depressed* at the time of referral. A number of factors contributed significantly to her stress; these involved interpersonal relationships within her family and also the burden of
care she was taking on in relation to her mother, who was a long stay patient in hospital, with a diagnosis of dementia.

The sessions focused on helping her to deal with her symptoms of anxiety and depression and to make positive actions that would assist her in breaking the cycle of depression. She worked well using a cognitive behavioural approach to intervention and over the year learned to cope with the symptoms of depression and also to take positive steps were meaningful in relation to putting change in place in her everyday life.

As her medical skin condition had improved significantly and as she was no longer in the moderate to severe range of depression, she did not require further professional intervention in relation to psychotherapy.

**Patient 5: Satisfaction Questionnaire**

<table>
<thead>
<tr>
<th>1. Benefit from CP session</th>
<th>very helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Improvement in QoL:</td>
<td>somewhat</td>
</tr>
<tr>
<td>3. Improvement in skin condition: very much</td>
<td>very much</td>
</tr>
<tr>
<td>4. DLQI before the session:</td>
<td>18</td>
</tr>
<tr>
<td>5. DLQI after the session</td>
<td>15</td>
</tr>
</tbody>
</table>
**Patient 6: Psoriasis**

A 44 year old lady suffered from severe psoriasis for the previous year. She had also developed depression and was on antidepressants. She was very upset by her skin condition and had stopped socialising. In the past she failed to attend the Dermatology Clinic twice because she did not want to come out of her house. She was referred to the CP.

**Clinical Psychologist evaluation**

The psychological assessment confirmed that she was extremely stressed and it appeared that her social supports and extended family support were minimal. She had a long history of both physical and child sexual abuse that had contributed significantly to her current vulnerabilities.

Due to the nature of past abuse and issues around her parenting, it was considered that short term focused therapy on the symptoms of the depression were not the best option at that time. It was agreed that some longer term psychological therapy might be more beneficial and especially when it was offered in the context of a therapist who had specific training around abuse issues. She was advised to follow that course.
### Patient 6: Satisfaction Questionnaire

<table>
<thead>
<tr>
<th>1. Benefit from CP session</th>
<th>somewhat</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Improvement in QoL:</td>
<td>somewhat</td>
</tr>
<tr>
<td>3. Improvement in skin condition: very much</td>
<td>very much</td>
</tr>
<tr>
<td>4. DLQI before the session:</td>
<td>19</td>
</tr>
<tr>
<td>5. DLQI after the session</td>
<td>4</td>
</tr>
</tbody>
</table>

### Patient 7: Compulsive skin picking (CSP)

A 20 year old female had a long history of picking the skin of her arms and legs which had caused scarring. She had good insight into her difficulties: she acknowledged that she picked her skin when she was stressed or alone. She was able to identify a number of current stresses in her life that had been prevalent for the last 6-12 months including worrying about her own skin, her mother who had several medical problems and personal finance issues.

### Clinical Psychologist evaluation

Using the SCL 90R, she scored in the normal range in all areas of the assessment with the exception of interpersonal sensitivity and mild depression. A cognitive behaviour psychological approach was used. The concept of relaxation was introduced, which she found helpful in reducing her level of anxiety when stressed. In relation to the picking behaviour, diversion strategies and some challenging of her automatic thoughts were explained. At
the final appointment, she reported significant improvement as her mood was
much brighter and she was socialising more with friends.

**Patient 7: Satisfaction Questionnaire**

<table>
<thead>
<tr>
<th>1. Benefit from CP session</th>
<th>somewhat</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Improvement in QoL:</td>
<td>somewhat</td>
</tr>
<tr>
<td>3. Improvement in skin condition: very much</td>
<td>very much</td>
</tr>
<tr>
<td>4. DLQI before the session:</td>
<td>24</td>
</tr>
<tr>
<td>5. DLQI after the session</td>
<td>2</td>
</tr>
</tbody>
</table>

**Patient 8: Atopic Dermatitis**

A 17 year old girl had a history of atopic dermatitis since childhood. Topical
treatment did not improve her condition and she was started on
immunosuppressive therapy to control her condition. It was found that she was
missing time from her school and was depressed because of her itchy skin
condition. She was referred to the CP.

**Clinical Psychologist evaluation**

It was discovered that due to a number of overdose attempts in the past, she
was under treatment with a Child Psychiatrist and the family’s preference was
that they wanted to continue with that treatment.
**Patient 8: Satisfaction Questionnaire**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Benefit from CP session</td>
<td>very helpful</td>
</tr>
<tr>
<td>2. Improvement in QoL:</td>
<td>very much</td>
</tr>
<tr>
<td>3. Improvement in skin condition: very much</td>
<td>very much</td>
</tr>
<tr>
<td>4. DLQI before the session:</td>
<td>14</td>
</tr>
<tr>
<td>5. DLQI after the session</td>
<td>10</td>
</tr>
</tbody>
</table>

**Patient 9: Hidradenitis Suppurativa and Dermatitis Artefacta**

A 40 year old female with a history of HS for 15 years and had 13 surgical procedures for her skin condition. Due the severe nature of her disease, she was started on biologic treatment. Over time it seemed likely she was aggravating her symptoms by self-damaging her skin as she developed linear erosions and ulceration instead of typical HS lesions. She was referred to the CP.

**Clinical Psychologist evaluation**

From her assessment she appeared to be unwilling to accept a psychological interpretation of her problems because she tended to believe they were only physical. She stated that she had no thoughts of harming herself. As part of this assessment she completed a number of standardised assessments, which focused on her current symptoms and also on her personality. She scored in the normal range in all areas of the assessment.
This pattern suggested a need to project a good image, high moral values, good self-control and freedom from psychological problems or human weakness.

**Symptomatic patterns**

The pattern was consistent with that of an individual who psychologically viewed herself as being ill. She had diverse interests that included activities that were not traditionally associated with her gender. Although actual physical problems needed to be ruled out, she showed similarity to individuals with somatoform disorders. She declined further attendance with the CP.

**Patient 9: Satisfaction Questionnaire**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Benefit from CP session</td>
<td>somewhat</td>
</tr>
<tr>
<td>2. Improvement in QoL:</td>
<td>no improvement</td>
</tr>
<tr>
<td>3. Improvement in skin condition: very much</td>
<td>very much</td>
</tr>
<tr>
<td>4. DLQI before the session:</td>
<td>14</td>
</tr>
<tr>
<td>5. DLQI after the session</td>
<td>2</td>
</tr>
</tbody>
</table>

**Patient 10: Severe atopic eczema**

A 15 year old girl had severe atopic dermatitis since early childhood which did not improve on topical treatments. She had required oral immune-suppressive therapy for her condition.
During her visits, she was found to be very quiet and shy. After discussion with her mother, it was decided to refer her to the CP because she had such severe chronic skin disease and we were aware of recent family bereavements.

**Clinical Psychologist evaluation**

She was seen on three occasions with her mother in the Clinic. There had been a number of incidents of bereavement over the previous 18 months when her younger only brother and her grandfather had died.

On the first visit, she presented as being a shy young girl that was very clingy with her mother and found it very difficult to talk to the CP on her own. However, over the course of the next two sessions she relaxed and was able to talk more for herself.

As part of the assessment she completed the Beck Youth Inventory, which is an assessment that looks at childhood anxiety, depression and self-esteem. In relation to this assessment her current symptoms were within the normal range in relation of anxiety and depression; however, her anxiety symptoms were somewhat raised, but were not in the range that would indicate a clinical problem. Her self-esteem was just below average for a girl of her age in comparison to the normal group.
She was given a number of tasks to work on at home and these included moving back into her own bedroom, and becoming more independent in relation to everyday activities for herself. She was asked to take more responsibility for the application of the topical creams and treatment in relation to her atopic dermatitis.

**Patient 10: Satisfaction Questionnaire**

| 1. Benefit from CP session | very much |
| 2. Improvement in QoL: | very much |
| 3. Improvement in skin condition: very much | very much |
| 4. DLQI before the session: | 15 |
| 5. DLQI after the session | 1 |
Discussion

Discussion is divided in two parts:

(a). A brief discussion of the diagnoses made in the 10 patients

(b). The outcome of the referral to the clinical psychologist

(a) Compulsive Skin Picking (CSP)

Four patients (Case 2, 3, 7 and 8) were referred to the clinical psychologist with a diagnosis of compulsive skin picking (CSP).

CSP is a skin condition produced by the patient through repetitive scratching, without an underlying physical pathology. The patient often has a co-morbid mental illness (usually anxiety or a mood disorder). (Arnold, 1998; Krupp, 1997).

Unlike other self-inflicted dermatoses (e.g., dermatitis artefacta and malingering), the patient with compulsive skin picking acknowledges the self-inflicted nature of the lesions. The quantity of lesions varies, ranging from a few to several hundred, and the lesions are located in easily accessible places on the body (Gupta and Gupta 1986).

CSP primarily affects female patients (52 - 92%) and studies report a mean onset between ages 30 and 45 years (Gupta, 1987). CSP is characterized by clean, linear erosions, excoriations, scabs and scars that are frequently hypopigmented or hyperpigmented. Patients “dig” at their skin with their nails to
relieve itching or to extract imaginary objects that they believe are imbedded or extruding from their skin.

The lesions are grouped at sites of the body that are easily accessible and usually exposed, such as the extensor surfaces of the extremities, face and upper back. The excoriations present in various stages: dug-out ulcers, ulcers covered with crusts and surrounded by erythema, and areas receding into depressed scars (O'Sullivan, 1999). It may generate the “itch-scratch” cycle, which in some, develops into chronic dermatitis.

These lesions are a “cry for help” in response to the stress associated with undeveloped coping mechanisms. It was reported that the rate of manifestation of the lesions after situations that cause severe stress, such as illness, accident, and bereavement was 19%-33%, and that the lesions regress as the stressful situation disappears (Sneddon, 1975). Early diagnosis can prevent the illness from becoming chronic.

_Treatment_

Initially, _counselling_ should be supportive and empathic but open to other approaches as issues emerge. _Cognitive-behavioural approaches_ may focus on helping the patient understand the illness through education and finding alternative responses to the pruritic sensations (i.e. changes in assumptions and automatic thoughts about the symptoms themselves, the substitution of a
healthy ritual such as an oatmeal soak or distraction with other activities). The most difficult time for many patients is at night, when itching occurs while the patient is in the near-sleep state.

**Outcome for our patients with CSP**

Working closely with the CP alerted us to awareness that increasing stress in the patient’s life might present as new somatic concerns.

Our patients with low DLQI scores after the sessions could be simply due to the fact that their skin condition had improved but it should be remembered that these patients had chronic CSP and had previously utilised most of the dermatologic therapeutic options of intensive topical therapies, antihistamines and occlusive dressings. In the feedback questionnaire, three patients had found the sessions very helpful.

**Hidradenitis suppurativa (HS)**

Two patients (cases 5, 9) had hidradenitis suppurativa (HS), a severe dermatologic condition characterized by recurrent, suppurative disease manifested by abscesses, fistulas and scarring mostly affecting axillae and groin area. Patients therefore have to deal with chronic pain, discharge, and malodour. In addition, fatigue and an associated arthritis may arise and prevent individuals from performing even common, everyday tasks or from working.
It is note-worthy that an ano-genital location impairs the QoL of patients with HS most of all, but the occurrence of lesions on uncovered skin plays a crucial role in the stigmatization level. The need for comprehensive evaluation of quality of life in patients with HS appears to be very important.

*Treatment*

The sessions were focused on helping the patients to deal with their symptoms of anxiety and depression. A cognitive behavioural approach aims to allow the patient to cope with the symptoms of depression and also take positive steps that have been meaningful in relation to putting changes in place in their lives.

Outcome for our patients with HS: Patient 5 had very severe HS, although she had found it helpful to work with the CP. Her disease was incurable but controllable and CP had helped her in dealing with the stress. Her DLQI remained raised after the CP sessions probably reflecting the chronic nature of her physical condition. However, the mental state had improved so patient 5 did not require further professional intervention in relation to psychotherapy. Patient 9 is discussed below.

*Dermatitis artefacta (DA)*

Patients with this factitial disorder self-damage their skin. They will often deny all psychological disturbances and become angry, and even aggressive if confronted with the diagnosis. They will often decline referral to a psychiatrist. Thus they seek to control the management of their ‘condition’ on their own
terms. Attendance with a psychologist or a psychiatrist challenges them to address the underlying causes of their distress.

*Outcome for the patient with DA*

Patient 9, probably had HS but DA had become her primary problem and therefore she did not engage with the CP process on a deep or open level. In a sense the patient with DA constructs a cutaneous _disease_ which allows them keep appropriate care at a distance. The underlying problems are therefore not addressed.

The intimate relationship of the skin and the mind illustrates the importance of a different approach in caring for patients with skin problems. Habits related to psychological problems may lead to skin problems, particularly picking-related ones, such as compulsive skin picking, nodular prurigo and acne excoriée.

In the management of skin disease, as with any health problem, doctors should not limit themselves to treating the disease *per se*. In patients presenting with certain skin diseases, it is important to consider the broader perspective and adopt a holistic approach.

From studying these patients it is clear that there is a different type of consultation occurring for the patient – without the constant interruptions of a typical dermatology clinic there is the possibility of the patient talking, of them being listened to and of unburdening.
Feedback from the consultations with the CP included:

- **Clarity about a psychiatric diagnosis** e.g. we were unaware that patient 6 had a strong history of been abused in her past and CP assessment allowed referral to appropriate follow up.

- **Specific therapeutic tools** e.g. decreasing picking by relaxation/diversion strategies. e.g. this was seen in patient 7 compulsively picking her skin if she did not address her anxieties.

- **Refusal to engage** with the physician and CP: This was seen in patient 9 who did not want to engage in exploring her DA. This refusal can be permanent e.g. in a resolute patient with DA or temporary as in Patient 4, who could not engage with the first attempt at therapy but did when offered another chance at a later stage.

- **New confidential information yielded by psychotherapy** that rounds" out our knowledge and understanding of a patient and perhaps elicits compassion within us in our future dealings with them.
Conclusion

In the beginning the dermatologist’s task is to confirm or exclude a dermatological disease or to provide the best treatment for a particular skin disease. This may take some time and it is through optimal use of this time a therapeutic alliance will be created between the patient and the dermatologist.

When the dermatologist, together with the patient, has identified that there is a psychological component in the aetiology or in the consequences of the dermatological problem, a consultation with a psychologist or a psychiatrist may be proposed.

If a positive relationship has been established between dermatologist and patient, the patient will be more likely to accept psychological treatment. Sometimes, the consultation of a psychologist or psychiatrist is a necessary part of the diagnostic process, either to exclude or to assess the psychological aspect of the problem.

Dermatology patients are not clearly asking for psychotherapy at the onset. They are asking to be cured but the medical approach by itself may fail to do so. When they come for psychological care they are often unaware of what they need to change about their ways of thinking or behaviour. The cutaneous disease is their major problem.
In the consultation, the therapist can explore whether the psychological approach can be helpful for the patient and whether he is willing to undergo this process.

It is not an easy journey for anybody. Three patients had significant bereavements in their past that seemed to be a core part of their current psychological symptoms (Patients 1, 2 and 10).

Patient 4 had put his life partly on hold caring for elderly parents only to find he could not embark on an intimate relationship after their deaths - because of strong feelings of low self-worth after years of chronic severe psoriasis. Patient 5 had the parallel stress of caring for her mother with dementia and coping with severe hidradenitis suppurativa.

So, the need for collaboration of dermatology and mental health specialists in handling psycho-dermatology patients is clear. There is debate regarding how psycho-dermatology units should best operate and offer training. Mostly, these units are formed in dermatology departments and function under the name of psycho-dermatology with psychiatrists, psychologists, and dermatologists all working in proximity.

The presence of a psychologist in the dermatology unit makes the acceptance of psychologic treatment by patients easier. Psycho-dermatology requires a collaborative working space and an interaction between the Dermatologist,
Psychologist and/or Psychiatrist is important in increasing the patient’s compliance to treatment and effectiveness of the treatment.

We are building a new department and there is dedicated space identified for clinical psychologist sessions to allow this work carry on in parallel to the formal dermatology clinics.
Table 6.1 Questionnaires used

<table>
<thead>
<tr>
<th>Questionnaire</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>DLQI (Finlay et al 1994)</td>
<td></td>
</tr>
<tr>
<td>SCL-90R checklist (Derogatis 1976)</td>
<td></td>
</tr>
<tr>
<td>Minnesota Multiphasic Personality Inventory (MMPI) (McKinley 1944)</td>
<td></td>
</tr>
<tr>
<td>Beck Youth Inventory (Hodges KK 1985)</td>
<td></td>
</tr>
</tbody>
</table>
Table 6.2    Patient Satisfaction Survey proforma

Over the last year the dermatology service had the addition of a Clinical Psychologist to the team. It would be helpful to the team if you could provide us with your views on this service. This will help in relation to the future planning of the service. Many thanks for your assistance.

*Please circle your response to each of the following:*

**Q. 1** About how many times did you get to meet the clinical psychologist?.

- 0-3 session
- 4-6 sessions
- 7-10 session
- more than 10

**Q. 2** How helpful did you find the sessions with the Clinical Psychologist

- Very helpful
- Somewhat
- Not helpful

**Q. 3** In what way do you feel it was beneficial attending Clinical Psychologist?

Answer:

________________________________________________________________________

________________________________________________________________________

**Q. 4** How much do you think it helped improved your quality of life?

- Very much
- Somewhat
- No improvement

**Q. 5** Has your skin condition improved compared to your first visit?

- Very much
- Some improvement
- No improvement
## Table 6.3
Demographics of first 10 patients referred to Clinical Psychologist

<table>
<thead>
<tr>
<th>Case no.</th>
<th>Age/sex</th>
<th>Diagnosis</th>
<th>Psychological diagnosis</th>
<th>No. Of sessions</th>
<th>DLQI before sessions</th>
<th>DLQI post sessions</th>
<th>Outcome of sessions</th>
<th>Comments about sessions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>17/M</td>
<td>Atopic dermatitis: poor compliance</td>
<td>significant grief reaction but no depression</td>
<td>1</td>
<td>6</td>
<td>2</td>
<td>Compliance improved</td>
<td>Not helpful</td>
</tr>
<tr>
<td>2</td>
<td>74/F</td>
<td>Compulsive skin picking</td>
<td>sudden unexpected death of sister; difficult grief</td>
<td>4</td>
<td>9</td>
<td>0</td>
<td>Defaulted follow up</td>
<td>very helpful</td>
</tr>
<tr>
<td>3</td>
<td>40/F</td>
<td>Compulsive skin picking</td>
<td>anxiety disorder; good insight</td>
<td>10</td>
<td>8</td>
<td>2</td>
<td>Positive outcome: working 1 day per week; renovating home with partner</td>
<td>very helpful</td>
</tr>
<tr>
<td>4</td>
<td>66/M</td>
<td>Severe psoriasis and psoriatic arthritis</td>
<td>Anxiety with panic attacks and obsessive compulsive thoughts</td>
<td>3</td>
<td>13</td>
<td>2</td>
<td>Patient declined to work in these areas</td>
<td>very helpful</td>
</tr>
<tr>
<td>5</td>
<td>54/F</td>
<td>Hidradenitis suppurativa</td>
<td>Under stress caring for mother with dementia</td>
<td>10</td>
<td>18</td>
<td>15</td>
<td>No longer in moderate-severe depressive range; discharged</td>
<td>very helpful</td>
</tr>
<tr>
<td>6</td>
<td>44/F</td>
<td>Psoriasis</td>
<td>depression; Past hx of sexual abuse</td>
<td>1</td>
<td>19</td>
<td>0</td>
<td>Discharged</td>
<td>Somewhat</td>
</tr>
<tr>
<td>7</td>
<td>20/F</td>
<td>Compulsive skin picking</td>
<td>Mild range intellectual disability; Mild depression</td>
<td>7</td>
<td>4</td>
<td>2</td>
<td>Discharged to Open appointment</td>
<td>Somewhat</td>
</tr>
<tr>
<td>8</td>
<td>17/F</td>
<td>Compulsive skin picking</td>
<td>Low mood, suicidal tendency</td>
<td>1</td>
<td>14</td>
<td>10</td>
<td>Discharged</td>
<td>very helpful</td>
</tr>
<tr>
<td>9</td>
<td>40/F</td>
<td>Hidradenitis suppurativa and dermatitis artefacta</td>
<td>Dermatitis artefacta</td>
<td>4</td>
<td>14</td>
<td>0</td>
<td>Discharged (she was not willing to engage)</td>
<td>Somewhat</td>
</tr>
<tr>
<td>10</td>
<td>15/F</td>
<td>Severe atopic dermatitis</td>
<td>Anxiety, low self esteem</td>
<td>3</td>
<td>15</td>
<td>1</td>
<td>Discharged</td>
<td>very helpful</td>
</tr>
</tbody>
</table>
Chapter 7

Conclusions of the thesis
Conclusions

The following conclusions can be reached from this thesis with regard to the psychosocial impact on dermatology patients.

We confirmed the importance of a specialised clinic focusing on atopic dermatitis. In Chapter 3 we demonstrated that there is significant morbidity associated with AD and it has a significant impact on QoL on the child, caregiver and family as measured by the QoL measures and severity scores. Our results showed that attendance at a specialist clinic is of benefit to the patients and their families with improvement in these impact scores.

This work is further confirmation of the importance of the dermatologic nursing role in the management of this chronic dermatosis. A practical consequence arising from this and other research has been the development of a new dermatology department to house dedicated clinic space for nurse led clinics for atopic dermatitis patients. Within this space will be enhanced treatment facilities including a paediatric treatment and bathing room to demonstrate topical treatments for sick children. We know this approach will enhance outpatient based treatments and reduce costly inpatient admissions and this will be of importance in an era of financial rectitude.
Chapter 4 focused on a novel questionnaire that elicits dermatologic patient fears related to their condition and expectations of treatment. The work clarified that there are a wide range of fears or concerns, particularly in those with inflammatory skin disease and that the doctor was unaware of these in almost a third of consultations.

This easy-to-administer questionnaire enables the doctor to pinpoint exactly what is worrying the patient at that time in relation to their skin and focus on it during the consultation. It allows the patient to express these fears or concerns in their own words. In a sense this information is complementary to other tools like the DLQI. It helps put the current concerns and expectations of the patient at the centre of the consultation process. A further validation is required before this can be used in the wider clinical setting.

The patients are asked what they want from the doctor that day. There was reported satisfaction in most of the consultations from the patients. These simple questions are helpful support for the consultation process. The fact that the unblinded doctors were unaware of the patient’s concerns in a third of consultations makes this a simple tool to enhance communication in the consultation.

Chapter 5 studied delusion of parasitosis and confirmed what a difficult condition it can be to manage - partly because there is a divergence between
the patient's understanding of their symptoms and that of the doctor and partly because resistance by patients to the use of neuroleptic drugs makes it very challenging for the dermatologist to maximise their benefit. Half our patients had persistent disabling symptoms and were often isolated from partners and friends partly by their condition.

Bridging the gap between the patient's misunderstanding of their symptoms and acceptance of the current neuroleptic treatment path is really difficult to achieve. Empathy for the plight of these patients is important. A keystone of therapy seems to be encouraging patients to accept treatment with neuroleptics on the simple basis that they do appear to work for some patients – even if we cannot confirm to the patients exactly how they work.

Chapter 6 studied the aspects of a clinical psychology attachment within the dermatology clinic setting. Key findings were greater clarity about psychological factors in the background contributing to patients' problems, intervention to deal with cutaneous picking behaviour and support for those with chronic severe dermatoses. Dermatitis artefacta is an occult condition in that the actions causing damage to the skin are concealed.

For the clinician it is not always possible to be certain that the patient is self injuring - It can be a difficult diagnosis to make with certainty. So, it was helpful confirmation to see that the patient with dermatitis artefacta resisted engagement with the psychology service in much the way that she did with the
dermatology clinicians. The greatest benefit to the patients studied from the clinical psychology service seemed to accrue to those with compulsive skin picking.

What emerges from this thesis is awareness that structured questionnaires like the DLQI and CDQLI alongside the open questions in our fears/expectations questionnaire are tools that help quantify the impact of dermatoses on patients.

Access to the Clinical psychologist and/or psychiatrist, ideally within the dermatology department, may enable a more integrated psycho-dermatological approach for patients. We are currently building a new dermatology department and dedicated purpose built space has been assigned for this kind of work to develop further.
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