

A REPORT OF THE
ALL PARTY PARLIAMENTARY GROUP ON SKIN

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REPORT ON THE ENQUIRY INTO THE IMPACT OF SKIN DISEASES ON PEOPLE'S LIVES

'Having a skin disease is not just a complaint; it is a way of life – day in, day out, year in, year out, from morning until night, with no cure.' Evidence submitted by a woman with psoriasis.

1.0 Background

1.1 Skin diseases can have serious psychological, physical and social consequences for those who live with them and often for carers and family members. While diverse in nature, they may be physically disabling, disfiguring, painful, intensely irritating and distracting. There is evidence to show significant increases in behavioural problems in children with some skin diseases, and increased suicide ideation in adults.

'I spent twelve years of my life terrified of being exposed, scheming to avoid the days at school that involved sport, and on quite a few occasions planning suicide. I became a recluse with an overwhelming wish to die, but not quite having the courage to carry it out.' Evidence submitted by a man with vitiligo.

1.2 Those not directly affected by skin diseases tend to be dismissive of them or even to find them repellent, their indifference or distaste frequently being exacerbated by the misplaced assumption that skin diseases are contagious or that they are caused by poor hygiene. There may even be doubt in the public mind that skin diseases count as sickness in the ordinary sense of the word. Such views are reflected in the relative lack of importance accorded to skin diseases by the Government, health service managers and health professionals not directly concerned with dermatology, as well as by the public.

1.3 It was for these reasons that the All Party Parliamentary Group on Skin (APPGS) decided to conduct an enquiry to provide an insight into the impact of skin diseases on people's lives and to make recommendations on how this may more appropriately be taken into account in the development and delivery of health services. Initially, this enquiry focused on the psychological and social consequences of skin disease, but the title of the report more adequately reflects the nature of the evidence received.

1.4 Much of the evidence was concerned primarily or exclusively with skin disease-related quality of life and its measurement, but the enquiry also examined the costs of skin disease to the state and to society.

1.5 A specialist advisory committee was established to guide the APPGS in its enquiry. Members of the committee are listed in Appendix One.

1.6 The APPGS accumulated a large amount of evidence (listed in Appendix Three) from patient groups, consultant dermatologists, nurses, GPs, other health professionals, health economists and members of the public.

1.7 The APPGS took oral evidence from three witnesses in March 2003. A list of these witnesses is set out in Appendix Two.

1.8 A glossary briefly explaining the characteristics of the skin diseases mentioned in the report is set out in Appendix Four.

2.0 Summary

2.1 It is estimated that at any one time around 25% of the population has a skin problem that could benefit from medical care. Skin disease accounts for between 15 and 20% of a GP's workload.

2.2 Skin diseases can adversely affect almost every aspect of a person's life. They can also seriously affect the lives of carers and of other family members. Many skin diseases, including acne, eczema and psoriasis can result in disability levels equivalent to those experienced by patients with non-dermatological diseases such as angina, asthma, arthritis, back pain, bronchitis, diabetes and hypertension.

2.3 The psychological and social impact of skin disease on an individual is not directly related to the overall area affected or to the severity of the condition. However, being affected in visible places such as the face or hands seems to cause more distress.

2.4 Standards of dermatology training for non-specialist health professionals, especially for pharmacists and for doctors and nurses in primary care, is inadequate.

2.5 People with skin diseases place great value on the information and help provided by the skin patient support groups.

2.6 Data on the costs of skin disease is patchy. Some research has been done with eczema and psoriasis but little or none for other skin diseases. More research is needed in this field.

2.7 The Government classifies most skin diseases inappropriately as 'minor ailments'. Although excellent work has been done by the Department of Health's (DH) Action on Dermatology (AoD) programme, chiefly in response to the need to reduce waiting times, the current NHS priorities seem to be focused on mortality and cure. There is a clear need for quality of life to be put at the heart of all health policy development.

2.8 The psychological and social impact of skin diseases should be assessed and taken into account by clinicians when considering treatment and management options. Several quality of life measures, or questionnaires, exist; these should be used and the results incorporated into health-service planning when assessing priorities.

2.9 As with other areas of dermatology, research into the appropriate methodology to measure the impact of skin disease is lacking and funding is required to develop this area.

3.0 The Extent of the Problem

3.1 The first ports of call for many people seeking help with skin diseases are often their pharmacist, NHS Direct or the internet. Of the 66% of calls to NHS Direct that are dealt with by nurses, almost 8% relate to skin problems.

3.2 Skin disease accounts for between 15 and 20% of a GP's workload. Only 6% of GP prescriptions relate to skin disease and 4% of NHS retail sales are for dermatology prescription-only medicines.

3.3 Virtually all skin diseases are managed initially in primary care, and 76% of dermatology consultations in primary care arise from a small number of conditions: acne, eczema, psoriasis and leg ulcers. The prevalence of atopic eczema in children is around 15–20% and is increasing. Psoriasis affects 2% of the population and for the majority is a chronic disease. Clinically significant acne is present in 14% of those in the 15–24 age group. Also commonly seen are urticaria, rosacea, herpes simplex, shingles, vascular lesions, benign skin tumours, pre-malignant conditions, non-malignant skin cancer and malignant melanoma.

3.4 The proportion of patients GPs refer to secondary care varies considerably, depending on the skills and confidence of the GP. Overall, around 5% of all skin patients seen by GPs are referred, generally those with severe or difficult skin diseases. However, when the effect of skin disease on the quality of life of patients in primary care is compared with that of patients in secondary care, it is found to be as great.

3.5 The impact of skin disease on a patient is not always directly related to the overall area affected or to other parameters of disease activity such as redness or thickness of plaques. The site distribution and the attitude of the individual are of crucial importance.

Comparison with other Chronic Disabling Diseases

3.6 In a 1995 study in which 369 patients with psoriasis were asked to compare the condition with having asthma, diabetes or bronchitis, the majority of patients who did not have the comparative disease felt it would be worse to have these other diseases. In contrast, those patients who actually suffered from one of the three comparative diseases predominantly replied that it would be better to have the comparative disease than psoriasis, and very few thought it would be worse.

3.7 General health measures have been used to demonstrate that psoriasis has a similar impact on the lives of patients as does angina or arthritis. Similarly, in children a general health measure has been used to demonstrate the major health burden that atopic eczema incurs in the community, compared to the burden of asthma and ear, nose and throat conditions.

3.8 A study in 1999 used validated generic questionnaires to assess morbidity in 111 acne patients and compare it with morbidity in patients with other chronic diseases. Comparative quality of life data were available from a random sample of

9,334 local residents, some of whom reported a variety of long-standing disabling diseases. All quality of life instruments showed substantial deficits for acne patients that correlated with each other but not with clinically assessed acne severity. The acne patients (a relatively severely affected group) reported levels of social, psychological and emotional problems that were as great as those reported by patients with chronic disabling asthma, diabetes, back pain or arthritis.

4.0 Evidence of the Impact of Skin Disease on People's Lives

4.1 There is no generally agreed definition of health-related quality of life (HRQoL). However, the Long-term Medical Conditions Alliance (LMCA) offers a useful form of words: 'the subjective perception of satisfaction or happiness with life in domains of importance to the individual'. While decision-makers need some standard criteria, it has to be recognised that what is important to one person may be very different from what is important to another person with the same condition.

4.2 Key quality of life domains for people with skin diseases include any or all of the following: symptoms and diagnosis; treatment; self-esteem; physical functioning; psychological health; sleep disturbance; family relationships; social support; schooling; life-changing decisions and work; finance; social, sexual and leisure activities; sport; ethnic and cultural issues; and environmental issues.

Symptoms and diagnosis

4.3 The symptoms of skin diseases, which can be very severe, are often underestimated by those not directly affected.

'...I can't stand the sun on me. The only place I get any relief is in the bath, 20 minutes a time, then itch, itch, itch, red blotches everywhere. My husband and two sons don't realise what it is doing to me.' Evidence submitted by a woman with eczema.

4.4 Evidence indicated that the diagnosis of skin diseases, especially the rarer ones, can be protracted and uncertain. Lack of dermatology training for non-specialist health professionals, particularly those in primary care, frequently causes delay, and the diagnosis and treatment of some conditions can often be based largely on trial and error.

'In April 1998 I had severe pain in my left arm and shoulder for several days. This was followed by the appearance of itchy blisters on my upper legs. On visiting my GP, I was told I had chicken pox and the pain was osteoarthritis. The GP continued to treat me for chicken pox until June 1998 when she referred me to a dermatologist. By this time I had blisters on about 70% of my body... Many of the blisters had turned into sores and I had severe joint pain in my knees.

'My first appointment at the hospital was in September 1998 by which time I had blisters in my eyes, nose, ears, vagina, navel etc. The blisters were preceded by severe itching. In October 1998 they began treating me for dermatitis herpetiformis. It was not this illness. In November 1998, after more tests..., I was diagnosed with bullous pemphigoid.' Evidence from a woman with bullous pemphigoid.

Treatment

4.5 Many patients manage their skin disease themselves and for some this is a positive action, being in control of their own condition. Others do it because their experience of the medical profession is poor. Many GPs have little experience of, and even less empathy with, long-term chronic conditions. A sense of failure in the treatment of such a condition transfers negatively to the patient who 'does not want to bother the doctor' or, especially in the case of psoriasis, comes to believe 'there is nothing they can do'.

4.6 Although there have been advances in the treatment of psoriasis in recent years, many of the treatments have a negative impact on daily living and self-esteem. They involve a demanding, time-consuming and repetitive regime, often smell unpleasant and are messy, staining clothes, towels and bedding. Systemic treatments bring side-effects and the need for on-going monitoring.

'The obvious failure of my skin to respond to their best efforts puzzled and even irritated the doctors. I was suspected of back-sliding and not following doctors' orders to the letter... They issued yet stricter orders and redoubled their efforts: more cold tar ointment and baths, and more frequent and lengthy courses of out-patient ultra-violet light. Smearing on the evil-smelling, sticky, staining stuff could take up to two or more hours a day, soaking in it another hour or so. Visits to the clinic absorbed another five or six hours a week. In effect, I had a half-time job on top of studies or work just to follow the treatment. My clothes and bedlinen were stained. I smelled peculiarly like a newly paved road. When it rained, my hair gave off a rich and sickly odour.' Evidence submitted by a man with 47 years experience of living with psoriasis.

'...I struggled to the clinic on the other side of town (two buses away) with two children under five, four times a week for bathes, tar baths and lamps. Nothing ever stopped it though.' Evidence submitted by a woman with psoriasis.

4.7 There appears to be an assumption within the NHS that treatments for skin diseases must necessarily be inexpensive, partly perhaps because skin diseases are seen as 'minor ailments' and partly because treatments for them have not generally been costly in the past. Increasingly, this is resulting in new, more effective but more expensive treatments being denied to patients by trusts preoccupied with staying within their prescribing budgets.

4.8 In a UK survey of people with psoriasis, conducted in 2002, 39% of respondents were unhappy or very unhappy with their treatment, 29% said they had given up trying to find an effective treatment and 28% had not seen either a GP or a dermatologist for over a year. Many patients have given up treatments that, in their view, are more trouble than they are worth.

Disfigurement and self-esteem

4.9 In a recent survey of young adults with disfiguring skin conditions using the Hospital Anxiety & Depression Scale, 28% of the 94 people surveyed showed borderline or definite clinical levels of anxiety, 51% scored above normal levels for social anxiety and social avoidance, and 5% showed borderline or definitive clinical levels of depression. Using the World Health

Organisation quality of life measure, 46% scored below the norm on the psychological domain and 48% below the norm on the social domain.

4.10 The same survey indicated that many of those questioned thought their condition was very noticeable to others, which caused considerable distress among a significant proportion of the sample. The impact of skin disease on their lifestyles was significant – 67% of the sample avoided certain, mainly social, activities such as parties, meeting new people, having their photographs taken, situations in which attention was drawn to them (e.g. public speaking) and taking exercise (which might involve exposing affected areas). Many chose clothes that would cover the affected areas, summer being particularly problematic. Others adopted various behavioural strategies such as putting their hands in their pockets and shielding their faces when meeting others.

‘The spots did not disappear. Many spread into large, fiery, red patches. My body looked like one of those old atlas maps of the British empire. The affected areas scaled over to form thick, white plaques from which the skin peeled, crumbled and fell away. Wherever I sat or walked, I shed a shower of skin crumbs or dandruff-like powder. I looked and felt a mess.’ Evidence submitted by a man with 47 years experience of psoriasis.

‘I am 40 years of age. I live at home with my elderly mother. I am on the verge of bankruptcy with debts on credit cards. I have never owned a house or car. I have no savings or pension and I have never had a salaried job until the last 2 years. I now earn £7,500 a year at a freight company loading boxes onto a trailer, a menial, low-paid, unpleasant job.

‘I have no criminal record and no drug addiction problems. As a child and a teenager I was talented. I have 12 GCSEs, four Grade A ‘A’ Levels, two Grade 1 ‘S’ Levels. I gained a scholarship to Oxford University where I just missed a first. I was an excellent athlete; at school I was selected to represent West Yorks schoolboys at football and I was a member of the Oxford University football team.

‘So, what happened? The transition from a talented, healthy child to an ineffectual, ill, unbalanced adult resulted from chronic severe acne. The departure from health was so profound it almost destroyed me. My whole adult life has been a chaotic stumbling from one crisis to another, interspersed with total life collapses, a life of continuous ill-health.

‘It began at around the age of 16 with a typical adolescent complexion of scattered spots and pimples... Within a year, my face, neck, back and chest were covered in spots and inflammation. Some of the spots were so huge and painful they were more like boils.

‘It has taken me over 20 years to get the help I needed and now I’m virtually well. If you aren’t aware of the way in which acne leads to life disasters, I know the truth, and the truth and its implications are appalling.’ Evidence submitted by a man with 20 years experience of severe acne.

4.11 Society’s increasing pre-occupation with image creates mounting pressure on people with skin conditions to withdraw rather than face questioning stares, evident revulsion and sometimes outright hostility from others. The enquiry received many examples of prejudice and discrimination against people with skin diseases – people at work being required to use different towels from other staff and people being asked to leave public swimming baths, as examples. Numerous studies have shown

that people with eczema, psoriasis and other skin diseases feel stigmatised, especially because they anticipate rejection and feel flawed, guilty, ashamed and secretive. Rejection or hostility 'teaches' people with skin conditions to avoid situations in which they may occur, and this can result in considerable social limitation and isolation.

'[My daughter] suffers from terrible acne on her face, chest and back. The problems we face as a family (because we all feel my daughter's sadness with her) are being called a spotty bastard; being called a leper by a group of men in town; having people stare at her, often right up in her face; being called a tramp; being told she is ugly; she has been beaten up in the past.' Evidence submitted by the mother of a young woman with severe acne.

'In 1997, at the local supermarket a lady pulled her young daughter away from me, informing me loudly that I was dirty and shameless and would be given no chance to infect her child. It hurt to the quick.' Evidence submitted by a man with severe eczema.

4.12 The sense of stigmatisation is exacerbated if lesions bleed as a result of excessive scratching. In a 1988 study of psoriasis patients in Ireland, 72% avoided swimming, 34% avoided going to a hairdresser and 40% avoided participating in sports. Choice of clothes was affected in 64%, and 50% said that having psoriasis had inhibited their sexual relationships.

'Having a skin disease means I am constantly thinking about my appearance. I lack self-confidence. I worry about my spots bleeding or weeping in public. I worry about an angry spot with a yellow head appearing and not realising so everyone knows except me. If my skin is particularly bad I don't leave the house unless I have to.' Evidence submitted by a woman with acne. 'Having a skin disease means I am constantly thinking about my appearance. I lack self-confidence. I worry about my spots bleeding or weeping in public. I worry about an angry spot with a yellow head appearing and not realising so everyone knows except me. If my skin is particularly bad I don't leave the house unless I have to.' Evidence submitted by a woman with acne.

'I have necrobiosis which leaves a number of large red patches on my lower legs. This affects me in a number of ways... During the winter it itches but is manageable with cream. Summer is the time when I just want to chop my legs off. I am lucky enough to live in Cornwall with great beaches and lovely sand. Do I go to the beach each week-end. No – why would I? I have these horrid marks on my legs.' Evidence submitted by a woman with necrobiosis.

4.13 A study by DEBRA UK, the national charity working for people with epidermolysis bullosa (EB), received reports of people suffering overwhelming embarrassment leading to withdrawal from society with consequent lack of opportunity for making friends or forming partnerships. The fear often voiced by the severely affected that they will never meet a marital or lifetime partner appears justified since only 27% of those with recessive dystrophic epidermolysis bullosa enjoy such partnerships.

4.14 Virtually all of Cancer Research UK's (CR-UK) help-line nurses have received telephone calls, e-mails and letters from people – especially those who have had recurrent basal cell carcinomas on their faces – who are very concerned about the cosmetic outcome of treatments. CR-UK say that people with skin cancer have always been interested in new treatments that might result in reduced scarring or no scarring.

4.15 The medical condition herpes simplex, best known as the cold sore, has a disproportionate stigma attached to it when it occurs on the genitals.

Quotes from Herpes Viruses Association members explaining their feelings following infection: 'I saw myself as disgusting – still do.' 'Suicidal.' 'I felt dirty, ashamed, kept crying, no man will ever want me now. I worry all the time, feel like I'm a freak and the only one out there with genital herpes.' 'Total distress. Wouldn't dare have sex with anyone now. I'm on anti-depressants because I feel so embarrassed, ashamed and worthless.'

Physical functioning

4.16 Inflammatory skin diseases can affect people's physical functioning both directly and indirectly. The enquiry was told of one man with severe eczema on his face who avoids all social contact as far as possible so as to avoid speaking, which is painful.

'My joints ache. My walking is really bad some days because it makes my psoriasis crack, bleed and weep.' Evidence submitted by a 31-year-old woman with 24 years experience of living with psoriasis.

4.17 Leg ulcers, common in the elderly, are a chronic problem and the physical symptoms continue for a long time, often following a recurrent cycle. It is generally accepted that leg ulcers have an impact on people's quality of life, yet many health-care professionals do not really understand what it is like to live with a leg ulcer. They become intent on healing the actual wound and tend to forget about the whole person.

'You sit there with people who've had ulcers for about 13 or 16 years and you think, am I going to be here in 16 years' time? Is it not going to get any better? I've never seen anyone who's healed up.' Evidence submitted by the Tissue Viability Society.

4.18 Several skin diseases, including post herpetic neuralgia, cause almost intolerable pain. Psoriasis and psoriatic arthropathy – the arthritis associated with psoriasis – can be both painful and severely disabling. Several skin diseases, including post herpetic neuralgia, cause almost intolerable pain. Psoriasis and psoriatic arthropathy – the arthritis associated with psoriasis – can be both painful and severely disabling.

'I have suffered from post herpetic neuralgia since October 1996, after having a very severe case of shingles. Such was the pain that I could not bear any contact whatsoever with the area of the neuralgia. I spent my days in an armchair, leaning to one

side with my head on a shelf supported by a cushion, and my nights on a put-you-up futon bed next to a radiator, under a makeshift tent.’ Evidence submitted by a man with post herpetic neuralgia.

‘I am writing to you on behalf of my husband as he is unable to write at the moment due to arthritis brought on by the severity of the psoriasis he has suffered with for the past 45 years...’ Evidence submitted by the wife of a man with psoriasis.

4.19 Even those with the mildest form of epidermolysis bullosa (EB) are conscious of the constant need to protect their skin. Trauma can result from repetitive actions, minor knocks or friction, or it may occur spontaneously with no external stimuli. Many of the daily activities of living have to be modified as a result e.g. most rise early to treat lesions and carry out treatments before embarking on daily activities, repeating the process before retiring at night. The average time spent on this daily is estimated as 38 minutes with a range from 5 minutes to 3 hours. Travel to school or work is governed by the same need for vigilance to reduce skin damage. Crowded places or rough terrain must be avoided, and journey plans must minimise walking. Motorists often have adapted cars and many patients are so disabled they are confined to wheelchairs; 83% of EB patients have mobility problems.

Psychological health

4.20 In the 2002 UK survey of people with psoriasis, 77% of respondents felt that their psoriasis had led to a lack of self-confidence, 79% felt that it had caused emotional distress or anxiety and 44% felt that others saw them as being ‘different’ because of their psoriasis.

4.21 One study found twice the rate of psychological disturbance in children with atopic eczema compared with children without it. The difference was statistically significant for children with moderate and severe eczema, but not for children with very mild eczema. The findings indicated that school-aged children with moderate and severe atopic eczema are at high risk of developing psychological difficulties, which may have implications for their academic and social development.

4.22 In another study, 54% of parents reported behavioural disturbances, such as children being naughty, irritable, bad-tempered, easily bored and hurtful to other family members, during flare-ups of atopic eczema.

‘He gets upset and cries and says he hates himself on bad days. He asks why him – what can you answer? He gets annoyed if he can’t join in. We have bought him plastic gloves so he can join in more. He gets very nasty and frustrated when he’s tired from lack of sleep due to the scratching.’ Mother of a boy with atopic eczema.

Sleep disturbance

4.23 While 10–30% of all children experience sleep difficulties during infancy, in one study 60% of children with atopic eczema were reported to have sleep problems, and most had had sleep disturbance at some time. In pre-school children, this rose to 86% during flare-ups. Night-time itching and scratching caused delays in getting a child to sleep and night-time wakening required parental help leading to parental frustration and exhaustion in 64% of cases.

Neroli Wilson and her husband had very little sleep for six years. She explained that their son, Christopher, would get warm as he slept and wake up ripping his skin to shreds. She said they were, and continued to be, awake for large parts of every night. As a result, their health and their relationship had suffered; they were often unwell and could not think straight. She said that psychologically they felt very alone, helpless, hopeless and let down by the medical community. (Oral evidence)

4.24 Sleep disturbance in children with atopic eczema can disturb siblings as well as parents. In one study, 63% of siblings were found to be losing sleep. The impact can be profound and is said to cause 'family function failure'. The affected child may have difficulties at play, at school and in sports, leading ultimately to absences from school.

4.25 Sleep disturbance affects adults with eczema as well as children.

'Lack of sleep was a problem all my working life. Despite heavy sedation I only fell asleep after say 6 a.m.; it was then into a very deep sleep so I often over-slept with the result that I could be late for work.' Evidence submitted by a woman with lifelong eczema.'

Effects on the family

4.26 Parents of children with severe eczema may experience restriction of their social activities, difficulties over family holidays and an effect on their personal relationships. In one study, 66% of families said they did not lead a normal family life. Many children were not allowed a family pet. Family diet was often affected and there was restriction of use of household products such as washing powders and bath products.

Neroli Wilson said Christopher's eczema dominated their lives. 'In the mornings, I gave him anti-histamine medicine, then inspected his skin, putting a topical antibiotic on any infected areas and steroid creams on the scaly eczema bits; 30 minutes later, I put emollient over his whole body. During the daytime I was with him, constantly watching for scratching and applying creams. Every night I added an emollient to his bath and then we went through the whole skin review and treatment again. If his skin was bad, I would put wet-wrap bandages on. Then he took a different anti-histamine medicine.

'A lot of time was spent in appointments with doctors, having UV treatment and getting repeat prescriptions from the pharmacist. It was also important for me to spend a lot of time with Christopher in order to comfort him in his distress, talk to him and build his confidence.' (Oral evidence)

4.27 In one study of children with atopic eczema, 71% of parents described psychological pressures including feelings of guilt, exhaustion, frustration, resentment and helplessness, and 74% described a general burden of extra care relating to household cleaning and washing, preparing meals and shopping, for example.

'Our baby had skin problems before he even left the maternity unit. The next six months of his and our lives were hell. He couldn't sleep unless he was totally exhausted; he was constantly scratching and tearing at his skin; and he was constantly tearful. I gave up my job to look after him. Due to stress and lack of sleep, I was unable to return to work... He would have

flare-ups when he would go red from head to foot, so we were scared to go too far from the house in case it happened when we were out.’ Evidence submitted by the mother of a child with severe eczema.

4.28 Some mothers delay returning to work from maternity leave if their baby has eczema because of difficulties in finding a child minder or nursery where the child can be adequately cared for and skin treatments carried out. It can also be difficult to find babysitters competent to manage the child’s care.

4.29 In one study, 80% of adults with severe atopic eczema reported that their family life had been adversely affected by their condition.

4.30 In a separate study, 29% of parents felt that interpersonal relationships were adversely affected by caring for a child with atopic eczema. Tiredness from sleep loss caused friction. Some parents described themselves as being over-protective, which sometimes led to feelings of jealousy in the carer’s partner and in siblings. In two families, the atopic eczema was felt to be one factor in the breakdown of the marriage.

4.31 In the same study, 34% of parents felt that their ability to go out, to entertain and to pursue hobbies was reduced because of tiredness. Sporting activities, especially swimming, were often restricted. In addition, there were difficulties in finding suitable babysitters, and 23% of families were restricted in their choice of holiday because of sleeping problems, climatic change and the special requirements for creams, foods, clothing and bedding.

‘Holidays [for people with eczema] are problematic because of messy, time-consuming treatments and the resultant regularly stained and bloodied sheets. The linen provided can provoke severe reactions, presumably because of the biological preparations used in laundering. I have not encountered any hotels that could say how their linen was laundered. Thus it may be necessary to take pillow slip and sheets when going away.’ Evidence submitted by a 70-year-old woman with lifelong eczema.

4.32 Caring for a person with EB has considerable time implications. A study by DEBRA found that 47% of dressings and treatments were undertaken by the parent/carer. In addition, escort or transport services provided by parents/carers continue beyond the usual age of independent travel. Parents with a young child with EB are often unable to work outside the home because there must be someone on call in case the school requests help in treating blisters.

4.33 Ehlers-Danlos syndrome (EDS) is an inherited disorder in approximately 70% of cases. The remaining 30% occur as spontaneous mutations. Parents often experience guilt, perhaps more so in the former case because the parent knows at first hand the problems the child is experiencing and the extent to which quality of life is impaired. For parents and carers there is a tremendous responsibility because the slightest trauma may lead to serious injury in a person with EDS. It is extremely important that young people are supervised, and they often need to be taken to school because public transport is fraught with dangers, and is unreliable.

Schooling

4.34 Schools often have poor understanding of the problems faced by children with eczema and of the strategies for dealing with it. School staff are increasingly reluctant to supervise or carry out the application of moisturisers, being afraid of touching children and of child protection issues.

4.35 In one study, 60% of school-aged children with eczema had problems with school life on account of it. All were experiencing teasing and bullying, leading to parental anxiety. There was higher than average poor school attendance and an increased need for remedial lessons. This caused problems for working parents. For the child with atopic eczema to be bullied or ostracised is not only a source of misery but may also aggravate the skin condition. Although less common in children of school age, psoriasis can have similar implications for those afflicted with it.

‘I was classed as an alien throughout my childhood. I was spat on, teased and laughed at. I left school at the age of 14; I simply couldn’t take any more.’ Evidence submitted by a 31-year-old woman with 24 years experience of living with psoriasis.

‘Our 16-year-old daughter spends one to two hours daily tending her skin. She has only 75% attendance at school because of her eczema and has not received sufficient education to cope with important exams. And what career will accept 25% absenteeism?’ Evidence submitted by the parent of a teenaged eczema sufferer.

4.36 Isolation at school may occur if the child uses special facilities or is unable to join in activities with his or her peers. Children with EB may be excluded from sports, games or dancing, and for some even the companionship of playtime is denied them for fear of skin damage; 67% reported physical constraints. Making friends can be difficult as many children fear the child with a skin disorder, believing the condition to be contagious or unclean. Bullying and teasing occur and may extend to affected adults in the workplace.

‘People have treated my son as a leper; they think they can catch something from him. He suffers name-calling and cruel games that bring attention to his skin.’ Mother of a child with severe atopic eczema.

4.37 The enquiry noted the recent (March 2003) case of a boy who had to be withdrawn from a north London school because the head teacher insisted that he wear the standard uniform grey woollen trousers, which aggravated the eczema on his legs so much that he could barely walk, rather than cotton trousers of similar colour.

Life-changing decisions and work

4.38 Evidence indicated that skin disease can affect career choice and work in two distinct ways. Existing skin disease can limit work opportunities and result in prejudice and interpersonal problems in the workplace. Occupationally acquired skin disease can compel people to abandon their chosen careers.

4.39 The majority of the work-related evidence received by the enquiry concerned eczema and psoriasis. It is clear, however, that many other skin diseases can be similarly damaging, limiting opportunities at work, and causing functional and interpersonal difficulties in the workplace. Skin diseases may have a great, often hidden, influence on a patient's long-term earning capacity.

4.40 Not surprisingly, the extent to which choice of career may be influenced by skin disease depends on the overall severity of the condition, with career choices being influenced in 8% of patients with mild psoriasis and in 17% of patients with severe psoriasis. In a survey of patients with severe psoriasis, 40% were working. Of these, 59% had lost a mean of 26 days from work during the preceding year because of their psoriasis. Of those not working, 34% attributed this to their psoriasis. In the 2002 UK survey of people with psoriasis, 35% of respondents said their psoriasis had affected their choice of career or chance of promotion; and in a 1993 survey, 20% of the 1,972 adults studied reported that their choice of career had been affected by their atopic eczema.

4.41 There have been reported cases of the armed services denying access to those with psoriasis although the Psoriasis Association knows of applicants who have been successful on appeal. The Association also has members who have had long and successful careers in the army in spite of their psoriasis.

The enquiry was told by Ray Jobling that having psoriasis had changed his life because he had always wanted to go into the Royal Navy but was prevented from doing so by his condition. He noted that the medical examination for the Royal Navy had been the last test after a long series of exams and interviews and that he had been devastated not to be admitted. (Oral evidence)

4.42 The Psoriasis Association have reports from individuals who have lost their jobs in the health and care sector because of their psoriasis and from others who have been turned down for posts. They also have reports of people with psoriasis admitted to hospital with other conditions being treated as if they were contaminated. They comment that there appears to be a basic misunderstanding of the nature of psoriasis around issues of infection.

‘Applying for medical social work training, I was strongly advised that this was not suitable for someone with eczema, although I believe that after I qualified the same adviser held me up as a shining example to others.

‘My first secretary ostentatiously wiped our mutual 'phone after I had used it. Blood from elbow lesions often showed through a blouse, woollen jumper and cotton lab coat by lunchtime. There were many days when I could not stretch out my arms and really should have been applying emollients every 20 minutes, but this was not often practicable.’ Evidence submitted by a woman with lifelong eczema.

4.43 For people with EB, physical work such as building or plumbing, or jobs involving cooking, lifting or manual tasks, carry considerable risk of skin blistering and are often performed against a background of persistent pain. Working can

present serious problems for people with EDS, both because of the physical limitations and because of the amount of time spent seeing doctors and health-care specialists. Virtually everyone with pemphigus vulgaris has to stop work until drug control is found and by then many people have lost their jobs. Even when they are self-employed or find another job, most people are only well enough to work part-time at best. People with any of the several conditions that may result in extreme sun-sensitivity, including xeroderma pigmentosum (XP) and some forms of lupus (LE), may be unable to go out to work – or to anything else. Hidradenitis suppurativa frequently causes absence from work.

‘The main reasons for his absence from work this year has been an operation to remove an area of damaged skin from his right buttock... I eventually signed him back to work in August even though there were areas of skin that had not healed. Unfortunately, his condition is incurable and further areas of skin are likely to be affected in the future. He is therefore likely to need further operations. His other medical problem has been one of depression and I suspect this has been aggravated by worry about his skin condition.’ Evidence from a medical practitioner quoted by the hidradenitis suppurativa support group.

4.44 Work-related skin disease is common in hairdressing and beauty care, catering and food processing, cleaning, construction, engineering, printing, chemical production, health care, agriculture and horticulture and the rubber industry, often costing people their jobs.

4.45 The psychological and financial impact of job and career loss, litigation and re-training are profound. Inability to access disability benefits with consistency adds to the burden.

Social, sexual and leisure activities

4.46 Many skin diseases can seriously inhibit or damage personal relationships. The 1993 survey found that in 64% of the 1,972 adults studied, their eczema adversely affected their ability to concentrate on their studies and to enjoy normal social and leisure activities. In a separate survey, 57% of adults with severe atopic eczema reported that their sexual relationships had been affected by their condition.

‘I had personal experiences in my teenage years of attempts to form a relationship with the opposite sex being actively hampered with open mockery and ridicule. Although many face such difficulties, young adults need access to positive support; suffering ridicule in silence can cause more problems.’ Evidence submitted by a 37-year-old man with severe eczema.

4.47 In the 2002 UK survey of people with psoriasis, 59% of respondents felt that their psoriasis adversely affected their ability to socialise; 49% felt that it had prevented them from forming relationships; 54% felt that it had adversely affected their sexual relationships; 46% felt that it made people too embarrassed to go out in public; 79% said that it made them too embarrassed to go to the pool or beach; and 44% said that it made it difficult to meet new people.

4.48 Those severely affected by EB cannot work and depend on benefits. Consequently, socialising is limited by financial constraints. Opportunities for establishing friendships or relationships are reduced by transport difficulties or inability to participate fully and, for those with visible impairment, self-consciousness can inhibit them from joining hobby or interest groups or attending social events.

4.49 Latex allergy requires reorganisation of the sensitised person's lifestyle because allergen avoidance needs to be practised in all areas – work, home and school. Although it is essential, this can be difficult because there are around 40,000 consumer and medical products containing natural rubber latex (NRL), and many of them are not labelled. The cost and time implications of identifying NRL content and substituting with latex-free alternatives can be considerable, both to sufferers and to their health-care providers. Access to health care is difficult and sensitised individuals often have to fight to secure this basic patient right. Nationally, two-thirds of operating theatres do not have latex policies and protocols in place, or latex-free equipment to deal with sensitised individuals. Some members of the Latex Allergy Support Group have reported being refused essential medical treatment because of their allergy.

'[She] looks like a perfectly healthy 37 year old. But everyday tasks that most of us take for granted could kill her. She can't eat salad, lick an envelope, use a calculator, blow up a balloon, rub out a lottery scratch card or paint the walls. She cannot lead a normal life because she is allergic to the proteins found in latex.' Evidence submitted by the Latex Allergy Support Group.

4.50 Evidence strongly suggests that herpes simplex has devastating effects on people's sex lives. Other conditions cause similar damage.

'Worst of all, I stay in wrong relationships because I feel lucky anyone could even begin to find me attractive.' Evidence submitted by a 53-year-old woman with 46 years experience of psoriasis.

'I met and married my husband in 1960. In all those years he has never once complained or been hurtful in any way. He deserves a medal. Can you imagine cuddling up to a wife with polythene bags on her feet and polythene gloves on her hands who rustles every time she moves?' Evidence submitted by a 64-year-old woman with 50 years experience of psoriasis.

'Pemphigus has a huge impact on partners. Again and again we hear of people whose marriages have been damaged or broken down because of their partner's inability to believe how ill a 'mere' skin disease can make someone. Sexual activity may become severely limited when lesions affect genitalia.' Evidence from the Pemphigus Vulgaris Network.

'I did start another relationship. I kept it platonic for six months and then, when he spoke of marriage, I had to tell him about the virus; the most degrading thing I ever had to do! Within a month, the 'phone calls had gone from every night to once a week to nothing at all. So, as you can imagine, I've never got involved since.' Evidence from a woman infected with herpes simplex by a previous partner.

Sport

4.51 People with skin disease may encounter physical and psychological barriers and thus feel uncomfortable with the idea of physical activity because of anticipated pain, discomfort and embarrassment. By shielding their condition or abstaining from physical activity, they minimise these uncomfortable feelings. These barriers may cause lifestyle limitations such as decreased social interaction.

Steve Lewis said that he had been a regional swimmer but that as his acne had got worse, he swam less and less until he gave up altogether. He said that he had to build up his confidence to get back in to a swimming pool at the age of 20 and that he still found it hard to remove his T-shirt and expose his scars in public. (Oral evidence)

4.52 It is recognised that physical activity can lead to enhanced psychological well-being and improved quality of life, in the areas of control and self-esteem, for example, increased confidence, better cognitive functioning, reduced anxiety and stress and decreased depression. However, people with skin diseases, particularly moderate to severe sufferers, may experience the opposite and therefore approach physical activity with caution, if at all.

4.53 The 1993 survey found that of the 1,972 adults studied, 83% of the women and 71% of the men reported that their eczema adversely affected their ability to take part in sports, to enjoy hobbies and to look after their homes.

‘My son and daughter were keen and proficient swimmers but had to forego this activity following the insensitive response from pool staff to the appearance of their skin, and the unwelcome attention of other bathers.’ Evidence submitted by the father of two children with severe psoriasis.

Ethnic and cultural issues

4.54 Skin diseases have specific significance and are associated with various beliefs and taboos in different cultures. In a multi-cultural society such as exists in the UK, it is important for health professionals to acknowledge that some of their patients from ethnic minority groups may have additional or quite different psychological and social needs from those of the majority of the population. Myths and beliefs about skin diseases can have a profound effect on the patient and affect their ability to cope. Understanding the implications of this is crucial to providing effective care for people with skin disease.

4.55 Vitiligo, the skin disease with no physical symptoms apart from loss of pigmentation from the skin, a predisposition to sunburn and in a few cases itching, none the less can cause great distress, particularly to people from India and Pakistan. This is partly due to the fact that from very early times this disease has been confused with leprosy, which can also cause white patches. The words used in some languages can be the same for both diseases (e.g. kilas or khusta), thus increasing the confusion. Therefore the reaction of families to any member developing vitiligo is likely to be fairly extreme; having vitiligo can mean being virtually outcast from the community. Examples of vitiligo destroying a woman’s marriage prospects are not

uncommon. There are also reports of a strong belief among Indians that vitiligo is a punishment for past wrongdoing or the result of a curse, a view supported by Dr Linda Papadopoulos' study on illness beliefs among vitiligo sufferers.

4.56 In people of African origin the loss of colour can threaten racial identity, adding another dimension to their psycho-social distress. However, this group usually has better support from members of their community than the Indian and Pakistani group. A 1994 study of African Americans with vitiligo suggests that this support is important in patients' adjustment to their condition.

4.57 Anecdotal evidence submitted to the enquiry suggests that ethnic minority families have such strong beliefs that eczema is contagious that they may experience added burdens of providing separate toilet facilities for the affected child (no shared bath for siblings) as well as a separate wash for clothes. Chaudhry et al used the Children's Dermatology Quality of Life Index and the Infant's Dermatitis Quality of Life Index to assess beliefs about eczema and what sort of help was sought for the condition among three racial groups, Caucasian, Indo-Asian/Black and Pakistani/Bangladeshi. The Pakistani/Bangladeshi group scored much higher than the other groups.

4.58 Generally, there is a great deal of anecdotal evidence to suggest that the stigma of skin diseases of all sorts within some Asian communities deters people from seeking medical assistance for themselves or for those in their care, which can lead to the disease going untreated, or being poorly treated, and thus to its exacerbation.

4.59 One aspect that is often not mentioned relates to gender. This may be particularly important in some cultures where a woman's marriage and career prospects may be damaged. Also, women bear the chief burden of support and treatment of family members with skin diseases. In the UK, there is concern about women from different ethnic groups who do not speak English and whose access to satisfactory medical care is frequently compromised by the lack of suitably qualified, sympathetic female interpreters.

'There is really very little research into the effects [of skin disease] on children and people from black and ethnic minorities, so how can we be said to provide equitable care?' Evidence submitted by a paediatric dermatology nurse.

Environmental issues

4.60 Skin diseases, especially atopic eczema which results from a genetic predisposition to allergy to house dust mite droppings, can impose significant environmental imperatives on those afflicted with it or their carers. These may include the removal of carpets and their replacement with boarding or linoleum; the use of thermostatic valves on central-heating systems to keep houses at acceptable temperatures; the replacement of soft furnishings with those less likely to harbour allergens; the purchase of special bedding and cotton bedclothes; increased emphasis on allergen removal, often including the purchase and frequent use of powerful vacuum cleaners and non-biological washing powders.

4.61 Other conditions, such as EDS and EB, may require the sorts of modifications to accommodation made necessary by any serious physically disabling disease, and conditions such as Lupus and XP that cause extreme photosensitivity may require considerable investment in light exclusion from the home and in the provision of light-excluding clothing.

Recommendations

- When a patient with a skin disease may be expected to benefit from a licensed treatment, that treatment should be made available to the patient.
- More research is needed to find effective treatments that do not place additional burdens on patients.
- Employers should be educated about the realities of skin diseases, and improved guidelines provided on managing skin conditions in the workplace.
- Dermatology departments should have in place systems to ensure that those most severely affected are seen and treated immediately when skin diseases flare up.

5.0 Support Services for Patients

5.1 Patients' needs arise from the disease itself, from the effects of the disease on their lives and from the process of care. Although there are excellent surgical and other techniques for the cure of various skin tumours, there are several inflammatory skin diseases that can be controlled only, not cured. In the absence of a cure, people clearly wish for the disruption to their lives to be minimised or reversed, but some of the treatments prescribed can add to the burden of the disease, at least in the short term. When being given advice and/or treatment, patients need understanding from knowledgeable carers and sympathetic staff. They should be able to express their concerns and have their worries allayed. These needs should be provided for efficiently with appropriate speed in a pleasant environment with privacy.

'I can remember only one doctor enquiring how I managed professionally, socially or emotionally. This was such a surprise I burst into tears.' Evidence submitted by a woman with lifelong eczema.

5.2 There is a serious shortage of health professionals specialising in dermatology, and coverage across the country is patchy. Those who are working in the field display a high level of commitment, provide an excellent diagnostic service and are able to intervene urgently if necessary. However, the levels of dermatology training among those who manage people with skin disease outside secondary care are clearly inadequate. There are also inadequacies in the management provided for some patients in secondary care, partly because of the current state of progress in science and partly because of resource restrictions. The inability to cure many of the inflammatory skin diseases and the only partial ability to relieve the consequent disruption to people's lives continues to be felt by patients against a background of many organisational and funding problems within the NHS.

Neroli Wilson said that she had expected support and information from the clinicians,

an individual patient plan and pro-active management, but that had not happened until they met the paediatric dermatologist. She expected information and demonstrations from a nurse about how to put on the creams and how to apply treatments, and she needed a health visitor to show her how they could adapt the house to lessen the impact of house dust mites.

(Oral evidence)

5.3 Chronic visible diseases can have marked adverse psychological effects on patients, and a number of skin diseases are exacerbated by underlying problems such as anxiety or depression. Dermatologists do not have the training or time to deal with these psychological problems adequately. Most consultant dermatologists are aware of the need for additional psychological support but there are too few experts in the field available to provide it. Those who are available could do much by training and advising nurse specialists as well as contributing to the patient's management.

5.4 The enquiry received a great deal of evidence of the practical implications of having skin diseases and of the extent to which the health and social services can fail to take account of them.

'I cannot go into hospital to have treatment as I have no-one to look after my children for six weeks at a time.' Evidence submitted by a woman with psoriasis.

5.5 Evidence also indicated that the psychological and social needs of people with skin conditions and disfigurements are largely neglected by present health services. This is a very similar situation to that experienced by people with other disfigurements whether they have been there from birth or were caused by accident, cancer or paralysis. All these groups have been found to experience especially high levels of anxiety, depression, difficulties at school, social avoidance and isolation, and unemployment.

New Approaches

5.6 Over the last ten years, effective new programmes have been developed to meet the psycho-social needs of people with disfigurements. Most of these are concerned with self-management and concentrate on teaching the social skills required to manage the reactions of other people to a disfiguring condition. This principle has been recognised, for example, in the new NHS specialist services being developed for children with cleft lips and palates. In some places, NHS professionals and policy-makers have incorporated these services so that their clinical practice includes all the elements relating to the patient's condition, not only physical, functional and aesthetic concerns but also previously neglected psychological and social problems.

5.7 A well-resourced research programme is required to develop psycho-social services for people with skin diseases. Various organisations exist in this area – the European Society for Dermatology and Psychiatry (ESDaP), and the UK Psychodermatology Group founded in January 2003, for instance, and work is being done at the Chelsea & Westminster Hospital to map current UK psychodermatology resources. Evidence indicates that best practice should include programmes geared to each level of care, including such options as:

- Joining with other relevant specialties to create Central Referral Units providing disfigurement-specific psycho-social programmes, to which patients with skin conditions could be referred by their GPs (such as the Outlook Unit, Frenchay Hospital, Bristol – soon to be replicated in Northern Ireland).
- Training specialist nurses/practitioners in dermatology to be responsible for managing the psycho-social aspects of disfiguring conditions (as exemplified by the Macmillan head and neck cancer nurse specialists).
- Making self-management resources available to all patients with skin conditions and their parents, such as the self-help guides and social skills video developed by the charity Changing Faces (eg: ‘When a medical skin condition affects the way you look: a guide to managing your future’).
- Creating outreach programmes for patients, including programmes for use in schools (such as those developed by Changing Faces), and informing patients about national and local support groups.

‘My husband, who had Gorlin Syndrome, underwent treatments for many years by surgeons who saw the physical problems. No support was available for the psychological impact until severe disfigurement and loss of sight had occurred. When it became available, the support came from the Trust he was transferred to for loss of sight and through the hospice and palliative care.’ Evidence submitted by the wife of a man with Gorlin Syndrome.

Discrimination

5.8 It is clear that many people with skin conditions find social interactions challenging and are often confronted by staring, curious questions, unwarranted comments, name-calling, verbal abuse, avoidance, rejection and discrimination. The enquiry received a substantial number of personal accounts from people who felt they had been discriminated against in work, leisure or as a consumer.

5.9 The Disability Discrimination Act (1995) (DDA) protects people with ‘severe disfigurement’ to their faces, hands or bodies from discrimination in employment and customer service. Although people with skin conditions might not consider themselves ‘disabled’ in the conventional sense of having a physical or mental impairment, it is important to establish that many of them, in common with people with cranio-facial syndromes, burn scars or other visible disfigurements, are covered by the DDA by virtue of the aesthetic effects of their condition. There have already been discrimination cases, some supported by the Disability Rights Commission, involving people with skin diseases where the claimant has won the argument, either settling out of court or being awarded damages by the Employment Tribunal or County Court.

Benefits

5.10 General lack of awareness of the psycho-social consequences of skin diseases almost certainly accounts for the fact that people with even the most disabling skin diseases are often denied benefits.

‘I tried to get disability living allowance three times but they have refused me, and not once did they look at my psoriasis.’ Evidence submitted by a woman with psoriasis.

5.11 Although pemphigus vulgaris is an extremely disabling disease to live with, most people with it have their benefit applications denied.

5.12 People with EB who accept the support offered by DEBRA-funded care agencies welcome the help they receive but many regret the lack of knowledge shown by the general public and their misconceptions about EB. There is resentment about the difficulties many face in obtaining appropriate benefits to meet the multiplicity of needs their disorder engenders. A further complaint is that, having established eligibility for benefits, they have to re-apply regularly despite having a lifelong disorder. The suggestion that all EB sufferers should have free prescriptions, as diabetes patients do, is frequently raised, as is the view that the disability living allowance (DLA) mobility component should be awarded to all on confirmation of a diagnosis of EB.

Information

5.13 It is recognised throughout medicine that well-informed patients make better recoveries, comply more readily with treatments and adjust better to altered body image and function. Information and education enables people to develop realistic expectations about outcomes and thereby to make appropriate psychological adjustment.

5.14 The quality of skin patients' lives can be improved significantly by quite basic things such as being provided with a simple, plausible explanation for a condition, advice from nurses, GPs and dermatologists, and more flexible access to help so that patients can receive it when it is needed – when their condition flares up or changes. Shortages of resources, training, specialists and support for doctors frequently prevent this, and the information gap often has to be filled by patient support groups, which are highly valued by sufferers.

'The positive thing was that a trainee GP found the address of the Lichen Sclerosus Support Group. It was from this that I gained a greater knowledge of the condition and realised I was not alone. There is self-help and also support from this important source.' Evidence submitted by a 70-year-old woman with lichen sclerosus.

Camouflage

5.15 The British Red Cross (BRC) Therapeutic Care Service provides professional advice and assistance to individuals in the use of cover creams to camouflage disfiguring skin conditions including vitiligo, rosacea, scarring, burns, skin grafts and port wine stains. This service is available free of charge in some hospitals through referral by a GP or a dermatologist and some of the creams are available on prescription. All practitioners are volunteers but costs of training new practitioners are high and funding is a major problem for such organisations.

5.16 The British Association of Skin Camouflage also has skilled practitioners providing private help at a modest cost. The Cosmetic Camouflage Network (CCN) is a professional body representing practitioners across the country with members drawn from both the BRC and the CCN.

5.17 Many clients have said that the above services have improved their lives significantly, by increasing their self-confidence and helping them to live a normal life. For vitiligo, the creams are the only licensed product available to patients. However, access to a trained camouflage practitioner is limited in certain areas. The biggest difficulty faced is lack of awareness both by clients and the medical profession of the benefits of this technique and the underfunding of this valuable service. The service is available free of charge in some hospitals through referral by a GP or a dermatologist and some of the creams are available on prescription.

Recommendations

- Cosmetic camouflage should be funded to ensure a benchmark service is offered in all parts of the UK, and made available not only in hospitals but also in GPs' surgeries and other community locations. Patients and health professionals should be made aware of the availability of the service via an information campaign.
- Research should be initiated to develop appropriate, effective psycho-social programmes to strengthen the self-esteem and self-confidence of people with skin conditions.
- All professionals providing services for people with skin conditions should be informed about the Disability Discrimination Act (1995) and be able to advise their patients how to take a case through the Disability Rights Commission.
- An assessment of the support services, facilities, education and information required to assist individuals with the impacts of skin disease should be undertaken, and best practice on the psycho-social support services available in the NHS circulated.

6.0 The Cost of Skin Disease

6.1 Data on the costs of skin disease to the NHS, and to society, is patchy. Some research has been done in the fields of eczema and psoriasis but there appears to be little or none for other skin diseases. This being so, the enquiry was unable to ascertain the cost of skin disease to the NHS.

6.2 The Health and Safety Executive reports that about four million working days are lost in the UK each year because of work-related and non-work-related skin disease. The total annual cost to industry runs into hundreds of millions of pounds. Work-related skin disease costs UK employers between £24 million and £59 million each year in sickness absence and re-training costs.

6.3 Almost all skin diseases impose additional costs on those affected by them. To qualify for Disability Living Allowance (DLA), the burden of proof lies with the individual who must prove the difficulties inherent in his or her condition. People with psoriasis score few or no points on the Invalidity Checklist, which is focused on motor functioning with some questions around mental state. There is no allowance for a condition that comes and goes, changes over time and can vary in severity. It is difficult to work in times of remission from severe psoriasis because of constant concern about another flare up, often exacerbated by the stress of work.

6.4 One study showed that special diets, extra laundry, bathing and clothes add to the cost of having atopic eczema but only four families (11%) felt that their lifestyle was changed because of this. In a minority, the financial impact was severe, with three families having financial difficulties.

Neroli Wilson said she was glad that prescriptions for children under 16 were free. She said that additional costs included anti-house dust measures such as buying a powerful vacuum cleaner and lots of cotton clothes and bedding, and that all the carpets in the house had had to be replaced with floorboards and lino. The house had to be kept cool, which required thermostatic radiator valves and they had bought a house with a north-facing garden. Mrs Wilson said she had had to take unpaid leave from work when her son's eczema was very severe. (Oral evidence)

6.5 Extra laundry and bedding add to the costs of looking after a person with EB, as do expensive specialised clothing, shoes and equipment. Where benefits are paid, they do not fully meet the costs.

'Being unable to work reduces one's income at a time when expenses become greater, e.g. paying for medicines. There are also knock-on effects – for example, when you don't have the stamina to go to the supermarket, you are forced to shop locally at higher prices.' Evidence submitted by a woman with pemphigus vulgaris.

6.6 People with Ehlers-Danlos Syndrome (EDS) often have increased costs in prescriptions because of pain and other factors, and must pay for splints, supports and aids to daily living, which are not provided by the NHS. Insurance such as critical illness, life, private health and travel are often hard to get or significantly loaded.

Recommendations

- More research is needed to establish the true costs of skin disease both to the NHS and to society.
- The Government should review the benefits system, making it more flexible to take account of long-term conditions the severity of which can vary over time.

7.0 The Need for Action

7.1 The Government classifies many skin diseases, including some chronic and disabling ones, as 'minor ailments'. This perpetuates the myth that skin diseases are trivial and inconsequential.

7.2 The NHS Plan published in July 2000 prioritised cancer, heart disease and mental health but made minimal reference to chronic conditions or quality of life. Given the Government's focus on mortality and cure, it is unsurprising that the disease areas that chiefly affect the quality of people's lives are high among those with the longest waiting times.

Neroli Wilson said that she did not think that quality of life was given any consideration in the development of health policy, and that the Government needed to recognise the impact that quality of life issues had for parents and carers and give them higher priority in developing health policy and allocating resources. (Oral evidence)

7.3 The demand for dermatological care has increased steadily in recent years. In the autumn of 2000, Action on Dermatology (AoD) was established to explore the challenges faced by dermatology services across England, to identify and develop ways of responding to them and to spread the knowledge and experience gained throughout the NHS. Capital funding was provided for the running of 15 pilot studies, the outcomes being incorporated into the Action on Dermatology Guide, which was published in January 2003.

7.4 Although funding for the AoD programme ceased in March 2003, a national AoD programme assistant director has been appointed to promote the Guide and encourage adoption and development of the good practice set out in it. Funding is also being provided for the appointment of local 'Action on' heads in the 28 Strategic Health Authorities (SHAs), to encourage adoption and development of the good practices developed by all 'Action on' programmes.

7.5 The AoD has brought significant improvements to dermatology but it has by no means solved all the problems. With 75% of NHS funding being devolved to 'the front line', dermatology will have to compete for funding with the NHS Plan's priorities of cancer, heart disease and mental health, and with other long-wait specialties such as cataracts, ENT and orthopaedics. There is a serious risk that variations in local priorities will perpetuate and exacerbate the present inequality in dermatology services that is evident across the country.

Recommendations

- Chronic skin diseases should either be placed in a category with comparable chronic conditions or be given a separate classification of their own in Government policy initiatives.

8 Educating Health Professionals

8.1 Up until now there has been little or no formal attempt to educate health professionals about the psychological and social consequences of skin disease. The effects may be perceived to be self-evident or a matter of common sense, or perhaps they are not recognised by disease and therapy orientated professionals and curriculum-setters. Most current five-year undergraduate curricula for medicine devote just one to two weeks to dermatology and so the opportunity to teach medical students about the impact of skin disease is very limited. At the University of Wales College of Medicine, medical students have the opportunity to take a five-week special study module concerning the impact of inflammatory skin disease on patients' lives, but this is available for three students only each year. Training for nurses includes very little opportunity for dermatology-specific education.

8.2 The Union of European Medical Specialities (UEMS) has an advisory role within the European Union, and the UK is represented on the dermatology and venereology committee. The 2001 basic curriculum for all trainees in Dermatology or Dermato-venereology across Europe includes the following: 'the trainee should gain knowledge of and gain experience in...psychodermatology and social aspects of...(dermatology)'. In the 1999 UK curriculum for specialist registrars training to become consultant dermatologists there is no specific mention of psycho-social aspects of skin disease.

8.3 Doctors and nurses involved in the care of people with skin diseases are daily made aware of the many ways in which these can affect the lives, activities and psychological well-being of their patients. This often leads to the belief that the best way these effects can be ameliorated is by the cure or suppression of the condition. The consultation may therefore be entirely focused on therapy as the best means to this end, and the patient may not be encouraged to express specific concerns, especially if the doctor or nurse does not feel equipped to offer useful advice.

8.4 Giving people the opportunity to tell their carer about the specific problems caused by their skin disease may be helpful therapeutically; and if carers are informed, they may be encouraged to create or learn about strategies that be used to cope with these problems.

Formal Measure of Quality of Life

8.5 Decisions regarding the management of people with skin disease need to take into account the effects of the disease on the affected person's life. The greater the impairment of a patient's life quality, the more likely it is that the person and their doctor will be prepared to consider treatment plans that might incur risk, inconvenience or cost. Other practical aspects of a person's daily life will also influence therapy decisions.

8.6 At present, the information concerning the effects of the disease is usually shared in a non-structured informal way, and the completeness of the doctor's understanding is often a matter of chance. Evidence suggested that dermatologists are not very accurate at estimating quality of life impairment in their patients. Therapy advice and clinical decisions are likely to be influenced by this often poorly informed perception. In a large study of people with psoriasis, many felt that their dermatologists were not being aggressive enough with their therapy, implying that their doctors underestimated the impact of the disease.

8.7 A formal recording or measurement of the impact of skin disease on people's lives may help with therapeutic decision taking. The most obvious areas where such data might be helpful concern the decisions to start systemic therapy, where there are often significant associated risks. At the moment, the information about the meaning of scores and the interpretation of score change is not sufficient to allow use of questionnaires in routine clinical practice. Validation of measures should be a priority area for clinical research.

8.8 Being able to assess the impact of skin disease is essential in order to understand and meet patients' needs. Apart from the potential for the information from quality of life measures to be used in daily clinical practice, there are several other reasons why measurement may be helpful.

8.9 New drugs are assessed using clinical measures such as the area of skin affected. It would be advantageous to have, in addition, a patient-orientated outcome. There may, for example, be a large improvement in a score of skin redness and scaling, but if the handicap experienced is only slightly improved because visible skin remains abnormal, the treatment may not have been successful from the patient's viewpoint. It has been argued that the concept of severe psoriasis should be based on quality of life measures rather than on, say, body surface area. The introduction over the last decade of therapies for eczema, psoriasis and acne has been supported by such information.

8.10 It is important to produce evidence of the effectiveness of care given, and to be able to monitor improvement against agreed criteria. Validated HRQoL questionnaires may be ideal for this. Their use can give insight into the acceptability of new methods of providing dermatology advice, such as teledermatology. Accurate epidemiological data is needed to plan health services: HRQoL data can measure the extent of problems caused by skin disorders and be used to compare the HRQoL of people with skin diseases to the general population.

8.11 Quality of life measures can be used to gain insight into patients' attitudes. As an example, it was identified that stress resulting from the anticipation of other people's reactions to their psoriasis was the major contribution to the variance disability reported by different people. The problems relating to compliance with treatment, often not recognised by dermatologists, need to be better understood. Quality of life indices have been used to provide more insight in compliance studies in psoriasis and acne.

8.12 People with skin diseases should be given appropriate priority for health care resource allocation. HRQoL data that demonstrates the profound effects of skin disease can strengthen these arguments. General HRQoL measures can be used to quantify the effects of skin disease compared to other system disease. It may be necessary to defend the value of dermatology clinical services that is self-evident to people with skin disease and to health professionals e.g. inpatient dermatology beds, patch testing, cosmetic camouflage advice and outpatient clinical services. Dermatology-specific measures can also be used to demonstrate the value from the patients' viewpoint of unusual treatment such as climate therapy.

8.13 How do quality of life measures relate to other clinical measurements? As expected, there is often a relationship between the clinical severity of skin disease and the impact that the disease has on life quality. This has been shown in children with atopic dermatitis. However, individuals show a wide variation in their responses to similar degrees of disease. The body site affected is a major influence with visible sites such as the hands or face causing more distress. The attitudes of other people vary widely and have a major influence on the degree of disability experienced. Clinical scoring systems may reflect changes that are not of relevance to a patient's life. Quality of life measures therefore should not be used instead of clinical measures as they assess a different, though interrelated, aspect of skin disease.

The Role of Quality of Life Data in Clinical Prioritisation

8.14 HRQoL measures are usually designed to assess the impact of skin disease at a particular time, such as ‘over the last week’. The impact over the long term may therefore not be reflected by these questionnaires. Skin cancer usually has little or no impact on current quality of life, but of course if the disease was not treated there could be major problems in the future. It is therefore important that if HRQoL data is to be used in deciding priorities for resources in the NHS, these measures should not be used in isolation.

8.15 Several studies have used general health measures in skin diseases. This data allows direct comparison with information from the same measures used in non-dermatological disease. In UK studies, people with severe psoriasis have higher scores indicating higher current quality of life impairment than people with hypertension or angina, and similar scores to people with asthma. Similar studies from the USA indicate that people with severe psoriasis have a similar level of life-quality impairment to people with arthritis.

Recommendations

- Urgent attention should be given to the provision of proper dermatology training for all GPs, nurses and pharmacists. The training should emphasise that most inflammatory skin diseases are long-term conditions and are likely to need on-going care, often throughout a patient’s life, and it should include awareness of the impact skin diseases can have on people’s lives.
- Specialist dermatology nurses should receive training in how to deal with the common psycho-social problems associated with skin diseases. Several organisations, including the charity Changing Faces and the University of the West of England, offer training and resource packs for nurses working with people with disfiguring conditions; these could easily be adapted to other conditions.
- Consideration should be given to establishing psychodermatology as a topic on the curriculum for trainee dermatologists, as recommended by the Union of European Medical Specialties (UEMS), and for specialist dermatology nurses.
- The Government should take properly validated, patient-assessed quality of life data fully into account in all health policy development and health service planning.
- HRQoL data on short-term and long-term impacts of diseases should be used to inform priorities for resource allocation in the NHS.
- HRQoL measures for skin diseases should be used in addition to clinical measures when assessing the treatment and management of individuals.

9.0 Quality of Life Research

9.1 Dermatologists and others caring for people with skin disease have probably always been aware of the impairment of life quality caused by skin disease. This area has been described in dermatology literature many times over the last century. However, formal research, involving the creation and use of methodology to measure this impact, is a relatively recent development. There are now several centres in major university hospitals in the UK and other European countries where

Health Services Research into this aspect of dermatology is being carried out. As with all aspects of dermatology, funding for such research is limited and highly competitive.

9.2 There are several different ways in which HRQoL can be measured. One uses fixed repeatable questionnaires, which are scored. A second approach uses questionnaires that allow a variable response, taking into account the particular issues that matter to the individual. Another method is to assess the value that people place on the presence or absence of disease states – the utility approach.

9.3 Some techniques are designed to be used across all disease states, some for use across a range of skin diseases and some for use in specific diseases. In many investigations, both a generic measure and a dermatology-specific measure have been used together. Most questionnaires are for use with adults but there have been methods described for measuring HRQoL in children with skin disease, and in infants with atopic dermatitis. The secondary impact of having a child with dermatitis on the family can also be measured.

General Health Measures

9.4 General health measures are designed to be used across a wide range of diseases. They are essential to compare the impact of skin diseases with the impact of diseases of other systems. Examples include the SF-36, the Sickness Impact Profile (SIP), the Nottingham Health Profile (NHP) and the EuroQol EQ-5D. The General Health Questionnaire is designed to detect psychiatric disorder. Many of these general health measures have been used in dermatology, for example in psoriasis, atopic dermatitis, acne and vitiligo.

Dermatology-specific Measures

9.5 Dermatology-specific measures are useful to compare the impact of different skin diseases, or to measure change before and after intervention in any skin disease. Having a single simple measure that can be used across all skin disease is advantageous in a busy clinical setting. The dermatology-specific measures that have been most widely used are the Dermatology Life Quality Index (DLQI) and Skindex. Other measures include the Dermatology Quality of Life Scales and the Dermatology-specific Quality of Life instrument. There is one general dermatology measure specifically for children, the Children's Dermatology Life Quality Index (CDLQI).

9.6 The DLQI consists of 10 questions covering a wide range of ways in which patients' lives are affected by skin disease. These include symptoms, embarrassment, interference with shopping or housework, clothes, social or leisure activities, sport, work or studying, personal and sexual relationships and the effects of treatment itself. The questions are answered by a simple tick-box method and each score 0–3. Validation studies have been carried out in the UK in secondary care and primary care and there are now over 150 references describing the use of the DLQI in a wide range of skin conditions and in many languages world-wide. Skindex has been developed in the USA and validated in three versions with 61, 29 or 16 questions. It has been used in psoriasis, along with the generic SF-36.

Disease-specific Measures

9.7 The questions in disease-specific measures reflect as closely as possible the problems encountered by people with that disease. These questionnaires are particularly suitable for comparison with same disease patients. In many skin diseases, however, people's lives are affected in similar ways, and so dermatology-specific measures can be used. There is no need for all skin diseases to have their own disease-specific measure. However, as well as those listed below, they are available for ulcers, urticaria, excessive axillary sweating, scalp dermatitis and for women with androgenetic alopecia.

Psoriasis

9.8 The stigmatising effects of psoriasis can be recorded using a 33 item questionnaire. Another technique for measuring this effect has been described and used to demonstrate the high stigmatisation experienced by patients with psoriasis compared to patients with other skin diseases. The stress that can be caused by the impact of psoriasis on quality of life can be measured by the Psoriasis Life Stress Inventory, in its 41 or 15 item versions.

9.9 A new method for recording the severity of psoriasis, the Psoriasis Salford Index (PSI), consists of three independent scores covering psycho-social disability, signs (disease activity), and history of interventions. This Index may be of great value in the recording and monitoring of the activity of psoriasis.

Atopic Dermatitis

9.10 The CDLQI and the DLQI have been widely used in the monitoring of patients with atopic dermatitis. Patient-assessed severity of atopic dermatitis has a stronger correlation with the DLQI and CDLQI than did doctor-assessed severity, emphasising the importance of direct assessment of attitudes of affected individuals. There are atopic dermatitis specific measures for use in infants, the Infants Dermatitis Quality of Life questionnaire (IDQoL) and for use in families of affected children, the Dermatitis Family Impact questionnaire (DFI).

Acne

9.11 The simple and compact five-question Cardiff Acne Disability Index (CADI) has demonstrated good reliability and validity. The Assessments of the Psychological and Social Effects of Acne (APSEA) questionnaire has 15 questions some of which relate to the overall impact and some to the recent past. A nine-item Acne Quality of Life Scale has been proposed, the questions relating specifically to social impact. The Acne-specific Quality of Life Questionnaire (Acne-QoL), which has 19 questions, has been validated but is not yet widely used.

Patient-specific and Utility Measures

9.12 HRQoL measures should be derived from information gathered from experiences of people directly affected and not from health-care professionals' concepts of what they suppose to be the impact of disease. Despite this, all fixed questionnaires suffer from the disadvantage that for an individual person, the weighting given to different aspects of life-quality impairment may be different from that assigned in the questionnaire, or specific issues may be missed. The Patient Generated Index overcomes these problems by asking patients to identify the five ways in which their lives are most affected

and then assigning them comparative values. This method is effective for identifying individual's specific problems as in atopic dermatitis, but it is difficult to use in large-scale before and after studies.

9.13 Utility measures use varying approaches to assess the theoretical value people place on their health. A simple 'financial value' method is to ask people how much they would be prepared to pay for a cure, if one existed. This has been used in acne, psoriasis and atopic dermatitis. Results indicated that 71% of people with severe psoriasis would be prepared to pay more than £1,000 for a cure and 38% would be prepared to pay £10,000 or more. These figures give some insight into the impact of the disease on individuals.

9.14 Another approach is to consider how much time people would be prepared to give up for the sake of a cure. These 'trade-off' questions can be related to shortening of life by years, as in the Quality Adjusted Life Year (QALY), or hours per day. Using the hours trade-off method, over 50% of adults with atopic dermatitis said they would be prepared to give up two or more hours each day if their skin would then be normal for the rest of that day. Curiously, there is no correlation between actual time spent on treatment and quality of life scores.

Children, Infants and Family Impact

9.15 The assessment of quality of life impairment in children is more difficult than in adults because of the changing ability of children to understand, rapid change in lifestyle at different ages, and different rates of maturing. The Children's Dermatology Life Quality Index (CDLQI) is for children from 4 to 15 years old. It has 10 questions and can be completed by older children unaided, but younger children need help. There is an illustrated validated cartoon version available, which children prefer and complete more rapidly. The use of the CDLQI in atopic dermatitis has demonstrated the benefits of inpatient admission, of a nurse consultant service, and the effect of new topical and systemic anti-inflammatory drugs. There are several different validated language translations of the CDLQI. Psycho-social screening in paediatric dermatology clinics can be carried out using the Pediatric Symptom Checklist, which consists of 35 questions answered by the parent.

9.16 The lives of infants with atopic dermatitis may be severely disrupted, and the Infant's Dermatitis Quality of Life Index (IDQoL) attempts to measure this by asking the parents to describe various aspects of their child's behaviour. A wide range of problems has been documented, including effects on mood, sleep, playing, dressing and bathtime.

9.17 Having a child with atopic dermatitis can have a major influence on the functioning of a family. The Dermatitis Family Impact questionnaire demonstrates the relationship of dermatitis severity to family life quality.

New Quality of Life Indices Required

9.18 HRQoL methodology is still at its early stages, with less than 20 years experience of its use. Consideration should be given to developing techniques whereby the problems experienced by patients are reflected better than they are now, but that retain simplicity to allow routine use. The areas of infancy, adolescence and the elderly require special attention, and there is

also a need to develop methods that are less reliant on language than at present, so that they can be understood across ethnic and language barriers.

9.19 From the affected person's point of view, the score for a predetermined set of questions may not reflect what is of importance to that individual person. Methods that take account of individual variation in importance are desirable, provided they remain simple. The secondary impact of skin disease on partners and families of those affected is a largely hidden burden of disease; further techniques are required to measure these areas. Virtually all methods of measuring quality of life relate to the current impact of skin disease on patients' lives. However, skin disease may have profound long-term consequences on major life decisions and so influence the long-term development and quality of life of individuals.

9.20 It is essential that people with skin disease are integrally involved in the development of quality of life measures. If health-care professionals or outcome-measure experts try to create questionnaires based on their secondary perceptions of the impact of skin disease, there will inevitably be major inaccuracies. Questionnaires designed to capture relevant information must be based on information coming directly from people with skin disease. The various measures described in this chapter are all based on such direct information.

Recommendations

- Funding should be made available for research into the creation and use of methodology to measure the impact of skin diseases on individuals.
- Further research is required into the long-term consequences on major life decisions and the influence this has on the development and quality of life of individuals.
- Funding should be made available for research on the psychological and social impact of rare diseases, which is often overlooked in favour of more prevalent conditions.

10.0 Conclusions

10.1 The evidence received highlighted the extensive impact skin diseases have on all aspects of people's lives from schooling, relationships, self-esteem and career choices to social, sexual and leisure activities. There was a clear sense of desperation, frustration and, in many cases, isolation.

10.2 Although research in this area has developed over the last twenty years, investment should continue and existing quality of life measurements should be integrated into the assessment of treatment and management options for patients.

10.3 It is clear that the impact of skin diseases on people's lives is not appropriately considered in their treatment. Furthermore, it is not taken into account in the development of Government health policy, which does not afford chronic conditions the priority given to other more life-threatening conditions such as cancer and heart disease.

10.4 Health policy in dermatology should incorporate properly validated, patient-assessed quality of life data to ensure that this aspect of health care is fully addressed. Health care should seek to ensure improvements in the physical symptoms of skin diseases but also aim to improve a patient's quality of life and, at the very least, reduce the burden of the disease.

10.5 Resources in this area of health care are lacking. The training of non-specialist health professionals is extremely limited. Psychodermatology should be included as a topic for every trainee dermatologist and specialist dermatology nurse. In addition, a code of best practice should be drawn up and circulated so that departments can incorporate, or implement, changes to ensure those individuals whose quality of life is severely affected have immediate access to treatment.

10.6 Relatively few skin diseases are life-threatening but, nevertheless, they can all have severe psychological, physical and social effects. These aspects of having a skin condition need to be understood and given due priority, so that patients with chronic skin diseases are provided with adequate and appropriate support to manage, control and live with the condition.

APPENDIX ONE

SPECIAL ADVISERS TO THE ENQUIRY

Maureen Benbow – Tissue Viability Nurse, Tissue Viability Society

Professor Andrew Finlay* – Professor of Dermatology, University of Wales College of Medicine, Cardiff

Coleen Gradwell – Dermatology Clinical Nurse Specialist, Queen's Medical Centre, Nottingham

Peter Lapsley – Chief Executive, Skin Care Campaign

Dr Linda Papadopoulos – Reader in Psychology, London Guildhall University

James Partridge – Chief Executive, Changing Faces

Maxine Whitton – Patient Advocate and Patron of the Vitiligo Society

Paul Miller – Health Economist

*Note: Professor Finlay is joint copyright holder of the following questionnaires described in chapters 7, 8 and 9 of the report: DLQI, CDLQI, PDI, IDQOL, CADI, ADI and DFI.

APPENDIX TWO

WITNESSES PROVIDING ORAL EVIDENCE

Ms Neroli Wilson – Management consultant and mother of child with eczema

Mr Steve Lewis – Mature student and former acne sufferer

Mr Ray Jobling – Chair of the Psoriasis Association

APPENDIX THREE

LIST OF WRITTEN EVIDENCE

Organisation Evidence Number

- M. Price, Consultant Dermatologist, Brighton & Sussex University Hospitals NHS Trust 1
- S.K. Kellett and D. Gawkrödger, 'The Psychological and emotional impact of acne and the effect of treatment with isotretinoin', Sheffield Teaching Hospitals NHS Trust and Keresforth Centre, Barnsley 2
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APPENDIX FOUR

GLOSSARY OF SKIN DISEASES MENTIONED IN THE REPORT

Acne An inflammatory skin condition, commonly affecting the face, chest and back.

Bullous pemphigoid A rare, blistering skin disease that can occur anywhere on the skin, most commonly seen in the elderly.

Eczema The commonest inflammatory skin disease, affecting up to 20% of children. The main features are itching, redness, dryness and scaling.

Ehlers-Danlos Syndrome (EDS) A group of inheritable disorders of connective tissue causing weakened skin, which is prone to bruising and tearing. Wound healing is extremely poor in EDS with resulting wide atrophic and unsightly scars.

Epidermolysis bullosa (EB) A group of genetically determined disorders, characterised by an excessive susceptibility of the outer layer of the skin and mucosae to separate from the underlying skin following mechanical trauma. The individual diseases vary in their impact from relatively minor disability (e.g. limitation of walking distance because of blistering of the feet), to death in infancy.

Gorlin syndrome A rare genetic condition in which patients typically develop multiple neoplasms, including basal cell carcinomas, and extreme sensitivity to sunlight.

Herpes simplex A virus that causes cold sores, whitlows on the fingers/hands and genital herpes. By adulthood, herpes simplex infection in the UK is around 50%.

Hidradenitis suppurativa A disease of the apocrine sweat glands, causing tender red nodules to develop in the groin and on the buttocks (commonly in men). The nodules are firm at first, but later become fluctuant, painful and eventually rupture, discharging pus.

Latex allergy Allergic reaction to rubber, either to the latex protein, a natural component of rubber, or to the chemicals used in processing natural rubber products. The effects of latex allergy range from a mild rash to anaphylactic shock, which can lead to death if untreated.

Lupus erythematosus An auto-immune disease in which the patient's immune system over-produces antibodies which then attack the person's own tissues. LE can occur in a number of complex ways, patients principally suffering extreme fatigue and joint and muscle pains. A variety of other symptoms are possible, as well as damage to vital organs if the illness has taken a strong hold. Some 50,000 people in the UK are thought to have LE, 90% of them female.

Necrobiosis Lipoidica Diabeticorum (NLD) Consists of oval plaques, usually on the lower legs. It may start as small red spots or raised areas, which develop a shiny, porcelain-like appearance. NLD is more common in women than in men and 60% of people with NLD are diabetic.

Pemphigus vulgaris (PV) One of a group of chronic, relapsing auto-immune diseases causing blistering of the skin and mucosal membranes. There are no definitive statistics but world-wide incidence of all types of pemphigus is thought to be approximately 0.5 to 3 per 100,000 per year.

Psoriasis There are several forms of psoriasis, which is caused by the overproduction of skin cells resulting in patches of silvery scales on top of areas of crimson skin. People with psoriasis are also prone to psoriatic arthropathy, a form of arthritis. Over a million people in the UK and Ireland have psoriasis, equating to 2% of the population.

Shingles and Post Herpetic Neuralgia Chickenpox is almost universal in the UK with 95% infection rate by age 21. The virus remains in the body and may reactivate causing shingles. Post herpetic neuralgia (PHN) follows shingles in a rising proportion of older patients, from 50% of 60 year olds to 70% of those aged 75 or over. PHN, which may last for months or years, causes very severe pain.

Vitiligo Estimated to affect 1–4% of all races and populations world-wide, including over half a million people in the UK.

Vitiligo causes patches of skin to turn white (these areas being very susceptible to sunburn) and, in some cases, hair to lose its colour in patches.

Xeroderma Pigmentosum (XP) A rare genetic disorder that may cause extreme sensitivity to the sun's ultraviolet rays. Unless patients with XP are protected from sunlight, their skin and eyes may be severely damaged. There are about 100 confirmed cases in the UK.

APPENDIX FIVE SUMMARY OF MAIN RECOMMENDATIONS

EVIDENCE OF THE IMPACT OF SKIN DISEASE ON PEOPLE'S LIVES

- When a patient with a skin disease may be expected to benefit from a licensed treatment, that treatment should be made available to the patient.
- More research is needed to find effective treatments for skin diseases that do not place additional burdens on patients.
- Employers should be educated about the realities of skin diseases, and improved guidelines provided on managing skin conditions in the workplace.
- Dermatology departments should have in place systems to ensure that those most severely affected are seen and treated immediately when skin diseases flare up.

SUPPORT SERVICES FOR PATIENTS

- Cosmetic camouflage should be funded to ensure a benchmark service is offered in all parts of the UK, and made available not only in hospitals but also in GP's surgeries and other community locations. Patients and health professionals should be made aware of the availability of the service via an information campaign.
- Research should be initiated to develop appropriate, effective psycho-social programmes to strengthen the self-esteem and self-confidence of people with skin conditions.
- All professionals providing services for people with skin conditions should be informed of the Disability Discrimination Act (1995) and be able to advise their patients how to take a case through the Disability Rights Commission.
- An assessment of the support services, facilities, education and information required to assist individuals with the impacts of skin disease should be undertaken, and best practice on the psycho-social support services available in the NHS circulated.

THE COST OF SKIN DISEASE

- More research is needed to establish the true costs of skin disease both to the NHS and to society.
- The Government should review the benefits system, making it more flexible to take account of long-term conditions the severity of which can vary over time.

THE NEED FOR ACTION

- Chronic skin diseases should either be placed in a category with comparable chronic conditions or be given a separate classification of their own in Government policy initiatives.

EDUCATING HEALTH PROFESSIONALS

- Urgent attention should be given to the provision of proper dermatology training for all GPs, nurses and pharmacists. The training should emphasise that most inflammatory skin diseases are long-term conditions and are likely to need on-going care, often throughout a patient's life, and it should include awareness of the impact skin diseases can have on people's lives.
- Specialist dermatology nurses should receive training in how to deal with the common psycho-social problems associated with skin diseases. Several organisations, including the charity Changing Faces and the University of the West of England, offer training and resource packs for nurses working with people with disfiguring conditions; these could easily be adapted to other conditions.
- Consideration should be given to establishing psychodermatology as a topic on the curriculum for trainee dermatologists, as recommended by the Union of European Medical Specialties (UEMS), and for specialist dermatology nurses.
- The Government should take properly validated, patient-assessed quality of life data fully into account in all health policy development and health service planning.
- HRQoL data on short-term and long-term impacts of diseases should be used to inform priorities for resource allocation in the NHS.
- HRQoL measures for skin diseases should be used in addition to clinical measures when assessing the treatment and management of individuals.

QUALITY OF LIFE RESEARCH

- Funding should be made available for research into the creation and use of methodology to measure the impact of skin diseases on individuals.
- Further research is required into the long-term consequences on major life decisions and the influence this has on the development and quality of life of individuals.
- Funding should be made available for research on the psychological and social impact of rare diseases, which is often overlooked in favour of more prevalent conditions.