The Burden of Atopic Eczema

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4.1 Introduction

Atopic eczema (AE) adversely affects the lives of patients, their parents, carers, and immediate family [20]. This immediate impact can lead to a profound long-term impact on patients' lives, by interfering with academic achievement, influencing or restricting career choice, affecting psychosocial adjustment and influencing friendships and choices over partners. The disease also may have a wider impact on society because of the financial and time costs for the individual and the health care system and because of reduced productivity of the patient. Although dermatologists have a unique insight into the impact of skin disease on their patients, they may not be as accurate as they may like to think concerning the accuracy of the estimation of their impact on individual patients [23].

It is important to recognise and understand the nature and extent of the burden that atopic eczema imposes, in order to develop appropriate strategies to alleviate the burden. This chapter describes the nature of the burden, reviews methods developed to try to measure the burden [18] and, in the absence of a cure, proposes some possible approaches to aid patients and those close to them.

It is essential to be able to identify and measure the impact of eczema on patients' lives. In the UK the All Party Parliamentary Group on Skin has recently published a report on the enquiry into the impact of skin disease on people's lives [1]. This report gives many examples of the effects of AE on patients and their families and is a potentially useful resource for political purposes. Its most significant recommendation is that the government should take properly validated patient-assessed quality of life (QoL) fully into account in all health policy development and that consideration should be given how health-related QoL data may be incorporated into health service planning.

4.2 Nature of the Burden

4.2.1 Infants

Very young children with AE have greater fearfulness and dependency on their parents than controls [10]. Although often too young to be able to express their feelings and experiences, the lives of preschool children may be severely affected by their condition: for the child they have known no other experience in life other than having dysfunctional itchy skin, disturbed nights and distress.

4.2.2 Children

AE can generate considerable emotional problems for children. For those over 5 years old, there may be problems from impaired performance at school because of sleep deprivation and time off school. Their social development can also be affected by poor self-image and lack of self-confidence.

4.2.3 Adolescents

AE can have a profound effect on the development of teenagers, impacting on their studies and level of academic achievement and on their social maturing. There is long-term influence on their choice of career and a realistic understanding of likely prognosis is essential if appropriate choices are to be made. Strategies are required to more effectively manage the psychological components of AE and other skin diseases in adolescents [44].

4.2.4
Adults

Persisting severe AE in adulthood places a severe long-term burden on the individual that is often not appreciated by others. Basic household chores, shopping, family outings, sports and hobbies may all be affected. There may be difficulties with close personal relationships, and patients' sexual lives may be adversely affected. Ability to optimally perform at study or at work can eventually have an economic impact.

Impairment of sleep is a major problem not only in children but also in adults with AE. There are also higher anxiety levels in people with AE [34], although there is no correlation between the clinical activity of AD and a measure of anxiety, and so psychological inferences should not be made from the severity of eczema. However, both the severity of AE and the anxiety of a patient contribute to the impact of AE on the QoL of the patient.

4.2.5
Secondary Impact on Family or Partner

There can be a substantial impact on family function resulting from having a child with AE. Parents describe feelings of guilt, exhaustion, frustration and helplessness. AE disrupts sleep in patients but also in parents and other family members. These impacts may be enhanced in lower income families who often have minimal social support mechanisms [29].

Three major factors were identified that were associated with high levels of impact of AE on QoL of the family: a perception by the parents that the child's condition is severe, high use of nonmedical services for the child's condition and financial concern about the child's condition [3].

4.3
Measurement of Burden

4.3.1
Psychological Measures

Patients with AE may experience stigmatization: a Questionnaire on Experience with Skin complaints (QES) has been described [41] to assess this: the genital region is especially relevant for the stigmatization experience both in patients with AE and with psoriasis. The stigmatization experience and QoL impact were not significantly different between similar groups of patients with AE and with psoriasis [42].

4.3.2
Quality of Life Measures

There are several reasons why it may be helpful to be able to measure the impact of AE on the QoL of patients. These include for clinical research to assess the outcome of treatment interventions using a patient-orientated outcome measure, for audit purposes to monitor the effectiveness of delivery of health care and potentially to inform clinicians when taking critical clinical decisions. In addition, measurement may have political benefits in strengthening arguments for additional resources for patients with AE. General concepts concerning quality of life measurement in dermatology have been reviewed [17].

Many different methods have been used to measure disease activity and outcome in AE and the criteria which need to be met were identified [15]. However, over the last decade there has continued to be wide variation in outcome methodology used in randomized controlled clinical trial therapeutic interventions for AE [5]. Of 93 eligible trials reviewed, only three used QoL measurements: the authors concluded that more emphasis should be placed on measuring things that are important to patients such as symptoms and quality of life. Although the SCORAD technique does include the QoL concept of a measure of sleep loss [47], the summation of this score within the sign score leads to lack of clarity in interpretation of the final score. New systems continue to be proposed for the assessment of AE, such as the Self-Administered Eczema Area and Severity Index (SA-EASI), which are sign- and symptom-based [25]. The authors of an objective severity assessment of atopic dermatitis score (OSSAD) [46] acknowledge that this measure might appropriately be used in conjunction with QoL instruments.

4.3.3
Atopic Eczema-Specific Measures

4.3.3.1
Infants

The Infants' Dermatitis Quality of Life Index (IDQoL) was created by interviewing a series of parents of young children with AE, in order to identify the ways in which the child's life had been affected by the disease [33]. This questionnaire reflects the many ways in which infants' lives may be affected.

4.3.3.2
Family Impact

Forty-one families with a child with AE were interviewed in depth to identify the key ways in which AD affects the quality of life of the rest of the family [30]. Over 70% of parents described a general burden of extra care and a similar number described psychological pressures. Over two-thirds said they did not lead a "normal" family life. The parents' sleep was disturbed, family relationships were adversely affected and holiday choices were restricted. The information gained by this survey was used to create a simple questionnaire, the Dermatitis Family Impact Questionnaire (DFI), which can be used to quantify these effects [30].

A further tool designed to measure the impact of AE by parents, the Parent's Index of Quality of Life in Atopic Dermatitis (PIQoL-AE) has recently been described [50]. However, this questionnaire primarily assesses the impact on the child's life.

In a cohort of children with AE aged 5 – 10 years in the UK, quality of family life (measured using the DFI) was significantly affected in 45% of cases at the first visit and in 36% cases 6 months later [4]. Quality of family life was related to the severity of the child's AE, as measured by SCORAD. This study emphasized the importance of parental assessment of the impact of AE as the disease affects the whole family. A similar relationship between AE severity and family QoL and between AE severity and children's quality of life impairment was demonstrated in a study in Malaysia [2].

4.3.3.3
Dermatology-Specific

The Children's Dermatology Life Quality Index (CDLQI) [32] is a suitable questionnaire to use in children with AE from the ages of 4 to 15 years, in order to measure the impact of AE. It has been used in several studies in children with AE: to assess differences in the impact of AE severity across different ethnic groups [6], to assess the impact of a nurse-run clinic in primary care on the QoL of children with AE [37] and to demonstrate the benefit of both topical tacrolimus [11] and oral cyclosporin [22] in AE. The CDLQI is now available in a cartoon version which has been cross validated to the text-only version [24]. This version is preferred by children and is completed more quickly, in about 90 s compared to 120 s for the text-only version.

In adults, the Dermatology Life Quality Index (DLQI) [19] is the most widely used general dermatology-specific measure of QoL. The DLQI consists of ten questions answered by a simple tick-box method. There is considerable experience of its use in AE with at least 20 published studies in this disease [31]. These studies have demonstrated that mean scores in AE are higher than for nearly all other skin conditions, stressing the major impact of AE on QoL. They also establish that the DLQI is a reliable measure which is sensitive to change in patients with AE. It is now possible to understand the meaning of DLQI scores using simple validated 'bands' of scores [24a].

Other dermatology-specific measures which may be used in adults with inflammatory skin disease include the Dermatology Life Quality Scales [36] and Skindex [8].

4.3.4
General Health Measures

The Pediatric Symptom Checklist is a brief psychosocial screening questionnaire which can be used in dermatology clinics. In one survey [38], 13% of patients screened positive: in this survey, AE was the largest single diagnostic entity. A Children's Life Quality Index (CLQI) has been described for use across all diseases: it can therefore be used to compare the impact of AE with, for example, chest or ear disease [13].

The Japanese version of the SF-36 has been used to assess the relationship between different physical characteristics of AE and QoL [21]. There was a strong relationship between symptom severity and pruritus in particular and QoL impairment: curiously, the location of the pruritic lesion on the neck had the strongest influence on self-perceived health status.

In the USA, the SF-36 has been used in a study of 239 patients and the results compared with those of patients with psoriasis and other non-skin disease [28]. Patients with AE had inferior mental health scores compared to patients with diabetes and hypertension. Compared to psoriasis, AE patients had inferior scores in vitality, social functioning, emotional and mental health domains. A study in Sweden also used the SF-36 to compare the QoL between psoriasis and AE [35]: this found no difference between these groups but demonstrated poorer health-related QoL in patients with psoriatic arthritis.

The UK version of the Sickness Impact Profile (SIP) has been used to measure the effect of oral cyclosporin on QoL in AE: this study [39] demonstrated the major improvement in QoL following therapy. The SIP is a 136-question instrument which can be used to compare the impact of skin disease to other nondermatological diseases.

4.3.5
Utility Measures

It is possible to gain an idea of the relative value that patients place upon their disease by means of so-called utility questions. These involve, for example, asking patients how much they would be prepared to pay or to give up for the sake of being free from their disease. In a study of patients with severe AE [16], on average sufferers would be prepared to pay the equivalent of three-quarters of 1 year's annual income for the sake of a cure. This type of approach is useful in the assessment of comparative attitudes towards disease and may give some insight into the severity of the disease from the patient's point of view.

4.3.5.1
Financial Burden

There is considerable variation of the costs associated with AE across countries [48]. In a community study in the UK, where the National Health Service provides health care without charge except for prescriptions, mean disease direct costs to the health service and family were £79.50 for each patient [14]. Indirect costs were not included. The annual direct costs of AE in children aged 1 – 5 in the UK for 1995 – 1996 was estimated at £47 million. In the USA, the annual third-party cost of illness for AE and eczema in the under-65-year-old population was calculated to range from US $0.9 billion to US $3.8 billion [12].

In the Netherlands, the total mean health-care costs of AE per patient per year were US $71 [48]: the most significant costs were due to visits to the general practitioner, US $32, and medication, US $21. An estimate in Australia of the yearly financial costs for a family and community, including medical, hospital, direct costs of treatments and indirect costs from loss of employment, range from Australian $1,142 per child with mild AE per year, to Australian $6,099 for a child with severe AE [26].

4.3.6
Impact of Therapy

This subject has recently been extensively reviewed by Schiffner et al. [40]. They concluded that at present there is a lack of controlled randomized studies evaluating different treatment modalities in AE and their impact on QoL and that it is not possible to answer the question "which treatment best improves QoL in AE?" They suggest that consensus meetings would be desirable to provide advice over guidelines for the selection and correct use of QoL measurements. They also recommend that patients' fears of side effects should be integrated into QoL measurements and that QoL measurements should be performed after a treatment-free follow-up period as relapse after treatment is frequent.

When cyclosporine microemulsion was used in a double-blind study to compare two different dose regimens in adults with severe AE, there was significant improvement in QoL in patients in both limbs of the study: body-weight-independent dosing seems to be feasible, with a preference for the 150 mg/day dose because of its better side effect profile [9].

Topical tacrolimus is effective in the treatment of AE, and in a study of 985 patients tacrolimus-treated groups experienced improved QoL relative to the vehicle control group. In children and toddlers there was also significant improvement in the active group in QoL except for the personal relationships scale [11]. A significant improvement in parent-rated QoL as measured by the PIQoL-AE was seen in children with AE treated with topical pimecrolimus [50].

A multicentre study across 29 hospital outpatient departments demonstrated that both in adults and in children with AE there was significant improvement in health-related QoL 6 weeks after consultation [43]. However, in many patients this audit revealed that the outcome was not as good as some physicians believe, indicating the need for an improvement in practice and a re-evaluation of working standards.

4.4
Strategies for Improving Burden

It has been suggested [29] that in the USA thoughtful changes of public policy could minimize the future socioeconomic toll of AE on patients and families. A Berlin education programme for parents of children with AE has the practical aims of improving parents' self-management skills concerning their child's disease, to positively alter the course of the disease and to improve the family's QoL [49]. This programme has had a desirable effect on treatment behaviour, satisfaction with new treatment, reduced rumination as an ineffective coping strategy and treatment costs [45].

Consultation with a suitably trained primary care nurse may be of value, especially in order to provide sufficient time to educate carers [7]. However, little impact on the QoL of children with AE or on family impact as measured by the DFI was detected in a study of 197 patients: additional outcome measures and studies in larger populations may be necessary. Similarly, although there was an improvement in QoL in patients following the introduction of a primary care liaison nurse, there was no significant difference compared to the control group [27].

4.5
Declaration of Interest

The author, AYF is joint copyright holder of several QoL measures described above, including the DLQI, CDLQI, IDQOL, CLQI and DFI. AYF receives honoraria for his membership of the Novartis Dermatology Advisory Board, UK. His department has received funding from Fujisawa.

References

1. All Party Parliamentary Group on Skin (2003) Report on the enquiry into the impact of skin disease on people's lives. All Party Parliamentary Group on Skin, London
2. Aziah MS, Rosnah T, Mardziah A, Norzila MZ (2002) Childhood atopic dermatitis: a measurement of quality of life and family impact. Med J Malaysia 57:329 – 339
3. Balkrishnan R, Housman TS, Grummer S, Rapp SR, Clarke J, Feldman SR, Fleischer AB (2003) The family impact of atopic dermatitis in children: the role of the parent caregiver. Ped Dermatol 20:5 – 10
4. Ben-Gashir MA, Seed PT, Hay RJ (2002) Are quality of family life and disease severity related in childhood atopic dermatitis? J Eur Acad Dermatol Venereol 16:455 – 462
5. Charman C, Chambers C, Williams H (2003) Measuring atopic dermatitis severity in randomised controlled clinical trials: what exactly are we measuring? J Invest Dermatol 120:932 – 941
6. Chaudhry S, Moss C, Gilmour E (2001) Quality of life measurements in children with atopic eczema from different ethnic groups in Birmingham. Br J Dermatol 145 [Suppl 59]:45
7. Chinn DJ, Poyner T, Sibley G (2002) Randomised controlled trial of a single dermatology nurse consultation in primary care on the quality of life of children with atopic eczema. Br J Dermatol 146:432 – 439
8. Chren M-M, Lasek RJ, Quinn LM, Mostow EN, Zyzanski SJ (1996) Skindex, a quality of life measure for patients with skin disease: reliability, validity and responsiveness. J Invest Dermatol 107:707 – 713
9. Czech W, Brautigam M, Weidinger G, Schopf E (2000) A body-weight-independent dosing regimen of cyclosporine microemulsion is effective in severe atopic dermatitis and improves the quality of life. J Am Acad Dermatol 42:653 – 659
10. Daud L, Garrada M, David TJ (1993) Psychosocial adjustment in pre-school children with atopic eczema. Arch Dis Child 69:670 – 676
11. Drake L, Prendergast M, Maher R, Breneman D, Korman N, Satoi Y, Beusterien, Lawrence I (2001) The impact of tacrolimus ointment on health-related quality of life of adult and pediatric patients with atopic dermatitis. J Am Acad Dermatol 44: S65–S72
12. Ellis CN, Drake LA, Prendergast MM, Abramovits W, Boguniewicz, Daniel R, Lebwohl M, Stevens SR, Whitaker-Worth DL, Cheng JW (2002) Cost of atopic dermatitis and eczema in the United States. J Am Acad Dermatol 46: 361 – 370
13. Emerson RM, Williams HC, Allen BR, Mehta R et al (1997) How much disability does atopic eczema cause compared to other common childhood skin problems? Br J Dermatol 137 [Suppl 50]:19
14. Emerson RM, Williams, Allen BR (2001) What is the cost of atopic dermatitis in preschool children? Br J Dermatol 144:514 – 522
15. Finlay AY (1996) Measurement of disease activity and outcome in atopic dermatitis. Br J Dermatol 135:509 – 515
16. Finlay AY (1996) Measures of the effect of severe atopic dermatitis on quality of life. J Eur Acad Dermatol Venereol 7:149 – 159

17. Finlay AY (1997) Quality of life measurement in dermatology: a practical guide. Br J Dermatol 136:305 – 314
18. Finlay AY (2001) Quality of life in atopic dermatitis. J Am Acad Dermatol 45: S64–S66
19. Finlay AY, Khan GK (1994) Dermatology Life Quality Index (DLQI): a simple practical measure for routine clinical use. Clin Exper Dermatol 19:210 – 216
20. Fiveson D, Arnold RJG, Kaniecki DJ, Cohen JL, Frech F, Finlay AY (2002) The effect of atopic dermatitis on total burden of illness and quality of life on adults and children in a large managed care organisation. J Managed Care Pharmacy 8:333 – 342
21. Fukuroku K, Nagano T, Ogino S (2002) Quality of life in patients with atopic dermatitis: using the Japanese version of the SF-36 health status questionnaire. Arerugi 51:1159 –1169
22. Harper JI, Ahmed I, Barclay G et al (2000) Cyclosporin for severe childhood atopic dermatitis: short course versus continuous therapy. Br J Dermatol 142:52 – 58
23. Hermansen SE, Helland CA, Finlay AY (2002) Patients' and doctors' assessment of skin disease handicap. Clin Exper Dermatol 27:249 – 250
24. Holme SA, Man I, Sharpe JL, Dykes PJ, Lewis-Jones MS, Finlay AY (2003) The Children's Dermatology Life Quality Index; validation of the cartoon version. Br J Dermatol 148:285 – 290

24a. Hongbo Y, Thomas CL, Harrison MA, Salek MS, Finlay AY (2004) Translating the science of quality of life into practice: what do Dermatology Life Quality Index scores mean? Br J Dermatol 151 (Suppl 68): 45 – 46

25. Housman TS, Patel MJ, Camacho F, Feldman SR, Fleischer AB, Balkrishnan R (2002) Br J Dermatol 147:1192 – 1198
26. Kemp AS (1999) Atopic eczema: its social and financial costs. J Paediatr Child Health 35:229 – 231
27. Kernick D, Cox A, Powell R, Reinhold D, Sawkins J, Warin A (2000) A cost consequence study of the impact of a dermatology-trained practice nurse on quality of life of primary care patients with eczema and psoriasis. Br J Gen Pract 50:555 – 558
28. Kiebert G, Sorenson SV, Revicki D, Fagan SC, Doyle JJ, Cohen J, Fiveson D (2002) Atopic dermatitis is associated with a decrement in health-related quality of life. Int J Dermatol 41:151 – 158
29. Lapidus CS, Kerr PE (2001) Social impact of atopic dermatitis. Social impact of atopic dermatitis. Med Health R I 84:294 – 295
30. Lawson V, Lewis-Jones MS, Finlay AY, Reid P, Owens RG (1998) The family impact of childhood atopic dermatitis: the Dermatitis Family Impact Questionnaire. Br J Dermatol 138:107 – 113
31. Lewis V, Finlay AY (2004) 10 years experience of the Dermatology Life Quality Index (DLQI). J Invest Dermatol Symp Proc 9:169 – 180
32. Lewis-Jones MS, Finlay AY (1995) The Children's Dermatology Life Quality Index (CDLQI): initial validation and practical use. Br J Dermatol 132:942 – 949
33. Lewis-Jones MS, Finlay AY, Dykes PJ (2001) The Infants' Dermatitis Quality of Life Index. Br J Dermatol 144:104 –110
34. Linnet J, Jemec GBE (1999) An assessment of anxiety and dermatology life quality in patients with atopic dermatitis. Br J Dermatol 140:268 – 272
35. Lundberg L, Johannesson M, Silverdahl M, Hermansson C, Lindberg M (2000) Health-related quality of life in patients with psoriasis and atopic dermatitis measured with SF-36, DLQI and a subjective measure of disease activity. Acta Derm Venereol 80 430 – 43
36. Morgan M, McCreedy R, Simpson J et al (1997)Dermatology Life Quality Scales – a measure of the impact of skin diseases. Br J Dermatol 136:202 – 206
37. Poyner TF, Sibley G, Chinn DJ (2001) The effects of a nurse-run clinic in primary care on the quality of life of children with atopic eczema. Br J Dermatol 145: [Suppl 59]:22 – 23
38. Rauch PK, Jellinek MS, Murphy JM, Schachner L, Hansen R, Esterly NB, Prendiville J, Bishop SJ, Goshko M (1991) Screening for psychosocial dysfunction in pediatric dermatology practice. Clin Ped 30:493 – 497
39. Salek MS, Finlay AY, Luscombe DK, Allen BR, Berth-Jones J, Camp RDR et al (1993) Cyclosporin greatly improves the quality of life of adults with severe atopic dermatitis. A randomised, double-blind, placebo-controlled trial. Br J Dermatol 129:422 – 430
40. Schiffner R, Schiffner-Rohe J, Landthaler M, Stolz W (2003) Treatment of atopic dermatitis and impact on quality of life: a review with emphasis on topical non-corticosteroids. Pharmacoeconomics 21:159 – 179
41. Schmid-Ott G, Kuensebeck HW, Jaeger B, Werfel T, Frahm K, Ruitman J, Kapp A, Lamprecht F (1999) Validity study for the stigmatisation experience in atopic dermatitis and psoriasis patients. Acta Derm Venereol 79:443 – 447
42. Schmid-Ott G, Burchard R, Neiderauer HH, Lambrecht F, Kunsebeck HW (2003) Stigmatisation and quality of life of patients with psoriasis and atopic dermatitis. Hautarzt 54:852 – 857
43. Shum KW, Lawton S, Williams HC, Docherty G, Jones J (2000) The British Association of Dermatologists audit of atopic eczema management in secondary care. Phase 3: audit of service outcome. Br J Dermatol 142:721 – 727
44. Smith JA (2001) The impact of skin disease on the quality of life of adolescents. Adolesc Med 12:343 – 353
45. Staab D, von Rueden U, Kehrt R, Erhart M, Wenninge K, Kamtsiuris P, Wahn U (2002) Evaluation of a parental training program for the management of childhood atopic dermatitis. Pediatr Allergy Immunol 13:84 – 90
46. Sugerman JL, Fluhr JW, Fowler AJ, Bruckner T, Diepgen TL, Williams MJ (2003) The objective severity assessment of atopic dermatitis score. Arch Dermatol 139:1417 – 1422
47. European Task Force on Atopic Dermatitis (1993) Task Force severity scoring of atopic dermatitis: the SCORAD index: consensus report of the European Task Force on Atopic Dermatitis. Dermatology 186:23 – 31
48. Verboom P, Hakkaart-Van L, Sturkenboom M, De Zeeuw R, Menke H, Rutten F (2002) The cost of atopic dermatitis in the Netherlands: an international comparison. Br J Dermatol 147:716 – 24
49. Wenninger K, Kehrt R, von Ruden U, Lehmann C, Binder C, Wahn U, Staab D (2000) Structured parent education in the management of childhood atopic dermatitis: the Berlin model. Patient Educ Couns 40:253 – 261
50. Whalley D, Huels J, McKenna SP, Van Assche D (2002) The benefit of pimecrolimus (Eledil, SDZ ASM 981) on parents' quality of life in the treatment of pediatric atopic dermatitis. Pediatrics 110:1133 – 1136