Measuring the Burden of Atopic Eczema in Young Children and the Family Unit

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The multidimensional impact of chronic skin diseases on the individual and their family unit has been, until recently, under-appreciated, and measurement has proved difficult because of its essentially subjective nature. Health-Related Quality of Life (HRQoL) measures were devised as an attempt to provide standardized quantitative data and a more meaningful and structured approach to patient care. Used together with physical measures of eczema severity, they can help to provide a more holistic approach to disease management and are perceived as a positive indication of the physician’s interest by the patient/family, helping to establish good rapport. It is to be hoped that the resultant improved patient/physician relationship may prove beneficial to treatment concordance and disease management (Carroll et al., 2005).

It is generally agreed that HRQoL measures should include items on physical, psychological, and social functioning and well-being, but frequently the content of domains are poorly specified (Eiser et al., 2001a). There are many variables to consider, which include age, gender, education, social class, ethnicity, and the respondent’s own psychological affect. Many scales lack precision regarding the content of domains of HRQoL, and most may not be culturally appropriate for all ethnic groups (Eiser et al., 2001a). A compromise has to be struck between scales that include many items that may be more able to capture maximum data in a research setting, versus scales with fewer items providing less data, but with the advantage of ease of use in a clinical setting. When investigating HRQoL it is essential to use existing questionnaires proven to be valid and reliable as a gold standard, and devising new ones should be avoided unless it can be shown that this provides extra and relevant data. Where new questionnaires are deemed essential, they should be validated (for construction, content, and criterion) and determined to be reliable (intra- and interobserver reliability and internal consistency). No single scale is likely to be ideal for all circumstances, and it is often useful to include a range of previously validated questionnaires. These could include a generic HRQoL, a measure of psychological stress and anxiety and a gold standard for the specific speciality or target disease, as well as the particular scale under development, and they should be appropriate for the age and ethnicity of the target population.

An important consideration when investigating HRQoL in children is the use of proxy measures, usually completed by the parent(s) or other caregiver. These are necessary for younger children or those with cognitive difficulties and can be used alongside child-reported indices for school-aged children. It should be recognized, however, that parental and child views on the impact of disease may vary, particularly in the case of subjective emotions such as sadness or embarrassment, although there is greater agreement over physical disability (Eiser et al., 2001b). Although many studies have shown that HRQoL impact increases with disease severity, it is important to remember that this relationship is not necessarily a linear one, but is dependent upon various factors, including body site and a person’s coping ability.

The rising incidence of atopic dermatitis in industrialized countries throws a large burden onto the family group, society, and health care resources. Some attempt has been made to measure the psychosocial and financial impact. Su et al. (1997) used a generic questionnaire for determining the effect of chronic disease on parent and families. This approach allowed direct comparison of families of children with eczema to those with other chronic diseases, such as diabetes and asthma. They concluded that families with moderate to severe eczema had a significantly higher impact on family score than families of diabetic children, and the financial cost of managing eczema both to the community and families was higher than managing asthma.

Use of the dermatology-specific Children’s Dermatology Quality of Life Index (CDLQI) has demonstrated that eczema and other itchy dermatoses have a greater overall impact on HRQoL than other common chronic diseases, such as acne or psoriasis in school-age children (Lewis-Jones and Finlay, 1995). This 10-item measure for school-age children provides a simple, rapid scale for everyday clinical use, but the small number of items may account for lower scores in diseases that have a large psychological impact but exhibit fewer clinical symptoms. Many studies, including our own, have found that children with eczema report itching, sleep loss, and problems at school as the most frequent and important items. A recent study in our department comparing the child versus parent’s perspective in eczema showed reasonably good agreement.1 Use of the Infant’s Dermatitis Quality of Life index (IDQoL) demonstrated that infants with eczema also have the greatest problems with itching, sleep loss, mood, and behavioral changes (Lewis-Jones et al., 2001). Other reported problems were discomfort with treat-

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1Beattie and Lewis-Jones: Brit J Dermatol, accepted for publication.
ment and difficulties with playing, bathing, dressing, and at meal times.

In a family study of eczema we used in-depth ethnographic interviews and brainstorming sessions to provide qualitative data for construction of the 10-question Dermatitis Family Index (DFI), and demonstrated a large psychological social impact on families of children up to age 12 y (Lawson et al, 1998). Eleven problem areas were identified, of which the practical difficulties of caring for a child with atopic eczema (skin care, feeding, shopping, washing, and cleaning), psychological pressures, physical exhaustion, and restriction of family lifestyle were the areas of highest impact. Other areas of life impact included sleep disturbance, financial, recreational, and family relationships. Financial pressures were rated as relatively unimportant for the majority of families (health care is free for children in the UK) but a minority, all single parent families, faced great financial hardship because of their child’s eczema. Parents rated the child being able to cope with their eczema as being of paramount importance. Balkrishnan et al (2003) used a modified version of the DFI for use in the USA and demonstrated that the parent/caregiver’s perception of clinical severity was the most significant predictor of impact of eczema on the family. The CDLQI, IDQoL, and DFI are validated and proven as reliable in many languages. Sensitivity to clinical change has been demonstrated and quantified for the CDLQI and DFI (Ben-Gashir et al, 2002, 2004), making them useful for clinical studies and outpatient audit purposes. The disadvantage of the brevity of these three measures is the relative lack of information they provide on the specific life domains affected, but they are useful for flagging problem areas for further exploration where appropriate.

In a study from Germany using several established measures, Warschburger et al (2004) examined the psychological adjustment in parents of young children with eczema and the impact on their quality of life. They found high rates of psychological stress, levels of which were directly related to the severity of the child’s eczema. McKenna et al (2005) recently published on the further development of the PIQoL-AD in several European countries. This 28-item scale measures the impact of eczema in families of young children and has promising validity, but has yet to be compared to other similar measures. They highlight the psychological impact of eczema and confirm the level of physical exhaustion suffered by parents due to the child’s sleeplessness. In this issue, qualitative data from Chamlin et al (2005) correspond well with the aforementioned and other family studies. They describe the development and initial validation studies of the Childhood Atopic Dermatitis Impact Score (CADIS). This novel measure for use by parents of young American children less than 6 y of age combines a proxy measure of the impact on the child (four subscales) and the impact on the family (four subscales) in 45 questions. The approach of combining the proxy measure for the child’s and the parents’ rating scale is, I think, an excellent one. They highlight the huge psychological pressure for parents, and it is a weakness, therefore, that they omitted the use of other validated HRQoL scales or measures of stress and anxiety as comparators, thus robbing them of the opportunity to obtain valuable additional information and validation. They are, however, not alone in this omission; use of comparative measures has been a failing of many HRQoL studies, including some of our own work. As the field of HRQoL expands, it is important that we use a more structured epidemiological and comparative approach if it is to advance beyond “infancy.”

Despite their shortcomings, HRQoL studies have done much to identify the terrible burden that childhood eczema places on the child and the family unit, which is currently unrecognized by health care analysts. The high world prevalence of atopic eczema and the other atopic diseases makes atopy one of the most important groups of all chronic childhood diseases. Identification of both the financial and psychosocial burden to individuals and society will enable us to argue for the appropriate necessary resources for disease management in the future.

References

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