Quality of life and childhood atopic dermatitis: the misery of living with childhood eczema

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SUMMARY
The misery of living with atopic eczema (syn. dermatitis, AD) cannot be overstated for it may have a profoundly negative effect on the health-related quality of life (HRQoL) of children and their family unit in many cases. As it is one of the commonest chronic relapsing childhood dermatosis (UK lifetime prevalence 16–20% by 20 years), with increasing worldwide prevalence, this has major social and financial implications for individuals, healthcare providers and society as a whole. This review explores the impact of AD on the lives of children and their family units and the use of some of the recently developed HRQoL measures, which have enabled investigation and categorisation of the physical, psychological and psycho-social effects of childhood eczema across all aspects of life. These effects include symptoms of itching and soreness, which cause sleeplessness in over 60%. Sleep deprivation leads to tiredness, mood changes and impaired psychosocial functioning of the child and family, particularly at school and work. Embarrassment, comments, teasing and bullying frequently cause social isolation and may lead to depression or school avoidance. The child’s lifestyle is often limited, particularly in respect to clothing, holidays, staying with friends, owning pets, swimming or the ability to play or do sports. Restriction of normal family life, difficulties with complicated treatment regimes and increased work in caring for a child with eczema lead to parental exhaustion and feelings of hopelessness, guilt, anger and depression. The hidden costs involved in eczema management can be significant and have particular impact on lower income families. The impairment of quality of life caused by childhood eczema has been shown to be greater than or equal to other common childhood diseases such as asthma and diabetes, emphasising the importance of eczema as a major chronic childhood disease. HRQoL measures are proving to be valuable tools for use in the clinical setting, as outcome measures for pharmaceutical studies, for health economics and audit purposes. It is therefore recommended that in future, they should be used in conjunction with objective measures of severity, as part of the assessment process of a child with atopic eczema. Lack of information on eczema and treatments heightens parental anxiety. Education of all individuals involved in the care of children with eczema is fundamental in the management of AD and it is essential to provide simple clear, unambiguous information on treatment and disease management in order to reduce the negative impact on HRQoL.

Keywords: Childhood atopic eczema; atopic dermatitis; family quality of life; health-related quality of life; CDLQI; IDQoL; DFI; PIQoL-AD; CADIS

INTRODUCTION
Atopic eczema (syn. dermatitis, AD) is the commonest childhood inflammatory skin disease, usually appearing in infancy before age 2 years and now affecting up to one in five children in the West to some degree (1,2). The UK lifetime prevalence is between 16% and 20% (2,3), and it has been increasing in most countries with a ‘Western style’ of environment over the last few decades. The 1 year prevalence amongst two groups of children aged 6–7 years and 13–14 years varied widely throughout the world from 15–20% in the UK, Ethiopia, Nigeria, Finland, Sweden, Eire and New Zealand to very low levels of 1–2% in Albania, Iran, China and Indonesia (1). The recent development of health-related quality of life (HRQoL) measures has enabled examination of the impact of eczema on children’s lives and that of their family unit. A community study to develop the Nottingham Eczema Severity Score found that although
approximately 80% of cases are clinically mild, over 25% of children with AD suffered continuous eczema associated with moderate to severe HRQoL impairment (4). Emerson et al. (5) also found that the atopic diseases as a whole caused the greatest HRQoL burden of all chronic diseases of childhood (5). In comparison with other such chronic diseases, Su et al (6) found that parents rated moderate to severe eczema as worse for the child than having diabetes and similar to having asthma. These findings are supported by work demonstrating that childhood AD may have a greater impact on HRQoL than asthma, diabetes, enuresis and cystic fibrosis (7,8). Children with AD also score higher for HRQoL impairment than those with the majority of other common skin disorders except for scabies (9) and psoriasis (8). Treatment for AD accounts for a significant amount of health service financial resources and clinical time, and places a burden on the child, family and society (10,11), with the potential for major impact on HRQoL. Use of different types of HRQoL measures has demonstrated the wide variety of ways in which AD can affect children and their families across all aspects of their lives from both the physical, social and psychological perspective (9,12–17).

PROBLEMS ASSOCIATED WITH CHILDHOOD ECZEMA

Sleep Loss

The cardinal symptom of itching causes scratching, which is associated with markedly disturbed sleep patterns for the majority of children (over 60%) (9,12,14,18–22). Sleep loss leads to physical and mental exhaustion for part or all of the family causing mood disturbance, loss of concentration and impaired performance at school or work (12,23). Parents may lose an average of 2.5 h sleep per night, particularly during flares of the disease (19), and Lawson et al. (12) found that 38% of siblings of children with AD also had disturbed sleep. The use of sedating antihistamines in children may further increase daytime tiredness and impair concentration. Children with eczema rate itching and sleep loss as the most important factors of their disease (8,9). Sleep disturbance may occur in several ways including difficulty in getting the child to sleep (sleep latency), frequent night-time wakening, reduced total sleep and difficulty awakening for school (19,23). Prolonged sleep latency and frequent night-time wakening have been shown to correlate with daytime behaviour and discipline problems (23). Although nocturnal awakening is common in up to 39% of normal pre-school children (24) eczema causes a pattern of much more frequent awakening and reduced sleep efficiency (22) with the potential for alterations in growth hormone secretion (25). During AD flares, 89% of infants in one retrospective study were found to have disturbed sleep patterns (19) and although sleep improved during periods of eczema remission it did not return to a normal in many cases. Chamlin et al. (26) recently reported on co-sleeping occurring because of atopic eczema in 30% of USA families interviewed, of which 66% were bothered by this. Cosleeping is the norm in many cultures and is not usually associated with distress; however, a child that is constantly scratching, even when asleep, inevitably has a negative effect on parental sleep patterns.

Effect on the Child

In infants scratching, sleep disturbance, miserable mood change, problems at meal-times, dressing and bathing, playing and treatment difficulties were found to be the predominant problems (14,20). Daud et al. (21) showed that 23% of pre-school children with severe AD had a significant increase in behavioural symptoms compared with 5% of matched controls. For the older child in addition to problems associated with itching, and sleep disturbance, their social and school life may be markedly affected (9). The ability to play or do sports, particularly swimming, may be limited because of embarrassment, discomfort and exacerbation of disease. Children with eczema frequently experience comments about their appearance which, even if well meaning, cause embarrassment (9). Many experience a feeling of social isolation and there may be peer-group rejection or even teasing and bullying, all of which may lead to loss of confidence, mood changes and depression (9). Tiredness from loss of sleep affects schoolwork causing impaired concentration, and children with severe eczema may lose time off school. In a US survey on AD the parents of 429 children up to age 15 years reported difficulties with school performance and daily social and leisure activities in 60% which related to perceived disease severity (27). All of these factors have an inevitable negative effect on education and may lead to the child becoming withdrawn or exhibiting difficult behaviour and even lead to the development of school avoidance/phobia. Dissatisfaction with messy treatments or bandages, having to wear particular cotton clothes rather than synthetic fashion garments, prevention from staying with friends or owning a pet are other particular problems (9). Interestingly and perhaps not surprisingly, parents and children differ in their views about which parameters of AD cause the most problem. In a recent survey Beattie and Lewis-Jones (8) found that children reported the greatest problem with physical symptoms but mothers rated the treatment as more of a problem for the child. Coping ability plays a large part in the perceived impact of disease so that although there may be an overall trend for severe and widespread disease to cause the greatest impairment in HRQoL, in an individual person this is not
necessarily the case. Severely affected patients can cope very well with minimal disruption to their lives, whilst others with relatively little objective evidence of disease may have greatly impaired HRQoL. There is also some evidence to suggest that parts of the body such as hands and feet may be more important than disease extent in causing an adverse effect on HRQoL (4).

Effect on Family Life

When caring for a child with eczema the difficulties and time-consuming nature of managing complicated skin treatments compound the impact of sleep deprivation on the parent(s). Su et al. (6) suggested that 2–3 h per day are required to look after a child with eczema and parents may also lose time off work and suffer financial loss as a result of caring for their child (6,10–12,28–30). Practical problems of everyday care are also of great concern and include increased laundry, house cleaning and food preparation, shopping and house dust mite regimes (12). Lawson et al. (12) found that over 90% of families reported problems with practical care, and this was flagged up as one of the most problematic areas for them. Inevitably, there are lifestyle restrictions for the family as well as the child, both at home and socially. This may include limitation of family diet, eating out, pet ownership and avoidance of certain household products such as soaps and perfumed products. Difficulties with coping with the child outside the home environment may restrict family holiday choice and there are often problems with finding appropriate childcare or babysitters (12). Negative comments from others about fear of contagion or the child’s appearance also cause great distress and blame is often felt to be apportioned by spouses or relatives (20). It is not surprising therefore that the majority of parents report feelings of frustration, hopelessness, anxiety, depression, anger and guilt, and the inability to cope (12,20). Indeed the psychological distress and the practical difficulties of caring for a child with AD are the most frequent and problematic aspects from the parents’ perspective (12,20) and often relate to the disease severity (26,31–34). Balkrishnan et al. (35) found that in a US study the perception that the child’s eczema was severe, high use of non-medical services and financial concerns correlated with the impact on family quality of life (QoL). A recent European study ‘Isolate’ (International Study On Living with Atopic Eczema) reported that parents felt that coping with the child’s eczema was one of the most important aspects to them, particularly where the eczema was severe (36). Insufficient medical and social support, conflicting advice from health workers and well-meaning family and friends increase parents anxiety and guilt (12,18,20,27). Lack of knowledge about treatments and their potential side effects is very common amongst parents and health personnel and is thought to be a significant contributing factor towards anxiety and lack of adherence to therapeutic regimes and treatment failure (12,36–38). Many are turning to alternative or complementary treatments, including dietary manipulation, as a result of these anxieties or a perceived failure of conventional therapy. Johnston et al. (39) found an association between the use of complementary medicine (CM) and ethnicity with over half (54%) those using CM citing lack of efficacy of conventional therapy and 17% concerned about potential side effects. A 1993 survey of over 10,000 members of the UK National Eczema Society found that parents wished for more easily available and understandable information (18). Education is therefore essential for all those involved in the care of children with eczema in order to reduce the negative impact on QoL and encourage treatment adherence (40–43). Ohya et al. (44) found that the strongest predictor of adherence to therapy was good doctor–parent relationships, which was more important than the mother’s anxiety about using topical corticosteroids. HRQoL measures have been successfully used as part of a parental training programme for the management of AD (40). In this study mothers, who were the majority of primary carers, experienced greater stress than fathers or other family members (41).

Psychological Disturbance

Atopic dermatitis can cause psychological difficulties for the child, parent(s) or other family members and may affect their interpersonal relationships (32,36,45–47). Psychological disturbance may also promote disease flares or affect clinical management. Absolon et al. (46) found double the rate of psychological disturbance in school-aged children compared with normal controls. In another study infants were found to be excessively clingy (50% vs. controls 10%) and fearful (40% vs. controls 10%) (21). Dysfunctional parent–child relationships have been found to occur in many cases of intractable childhood eczema (45) and when these are addressed there is ‘rapid and sustained improvement in skin, emotional development and social adjustment’. In a study of 187 parents of young children with AD Warschburger et al. (32) found a higher than normal level of psychological distress in the parents (mainly mothers) and a subgroup (those with children with chronic eczema) had extremely high levels. There appeared to be a direct relationship between parentally observed eczema severity and levels of psychological distress.

The Financial Costs of Eczema

There are many hidden costs to treating eczema over and above specific therapies so that personal costs may be high (6,28–30,48). These include loss of financial earnings
Parents of children with atopic eczema

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Health-related quality of life measures for childhood atopic dermatitis

Table 1

| Measure                                                                 | Age Range            | Description                                                                 |
|------------------------------------------------------------------------|----------------------|-----------------------------------------------------------------------------|
| *Children's Dermatology Life Quality Index* (CDLQI<sup>®</sup>)         | School-aged children | A 10-item scale, pertaining to previous week. Answers on a four-part Likert scale, maximum score 30 (high scores = greater impact of HRQoL). Available in 19 languages |
| *Infants' Dermatitis Quality of Life measure* (IDQOL<sup>®</sup>)       | Birth to 4 years    | A 10-item scale, pertaining to previous week. Answers on a four-part Likert scale, maximum score 30 (high scores = greater impact of HRQoL). Separate parents global severity score, five-part Likert scale. Available in 15 languages |
| *The Dermatitis Family Impact questionnaire* (DFI<sup>®</sup>)           | Parents of children with atopic eczema | A 10-item scale, pertaining to previous week. Answers on a four-part Likert scale, maximum score 30 (high scores = greater impact of HRQoL). Available in nine languages |
| *Parents Index of Quality of Life in Atopic Dermatitis* (PIQoL-AD<sup>®</sup>) | Parents of children with eczema aged 0–8 years | A 28-item scale with questions using needs-based approach and two-point responses pertaining to ‘the present time’. Tested in six languages |
| *Childhood Atopic Dermatitis Impact Score* (CADIS<sup>®</sup>)          | Children          | A 45-item scale pertaining to last 4 weeks with a five-part Likert scale (high scores = greater impact of HRQoL) |

(caring for a sick child), the cost of non-propriety treatments, special clothes and bedding, extra cleaning, special diets, and trips to the doctor or hospital (48). These costs have been found to relate directly to eczema severity and are comparable to or greater than other chronic diseases of childhood such as asthma and diabetes (6). Emerson et al. (29) found that family care costs accounted for 36% of total disease costs. In terms of importance of this to parents, although Lawson et al. (12) found that the majority did not rate personal financial costs as the most important aspect of life affected, single parent low-income families found this to be one of the most important negative aspects of caring for a child with AD. Indeed, all aspects of care may have greater impact in lower income families (10). In those countries without free health care optimal care for AD may not be possible without additional financial help.

Measuring Quality of Life

Quality of life in children has been defined as a measure of how a child views his/her life in relationship to how they could reasonably expect or desire it to be (49). HRQoL has also been defined as the capacity to perform the usual daily activities for a person’s age and social role (50). There are a large number of variables influencing QoL measurement (51). These include age, gender, social class, ethnicity, education, life experience, disease severity and family functioning (51,52). HRQoL can be measured in a number of ways but it is important that scales should be valid, reliable and with good repeatability (13,53). When constructing HRQoL scales there is always a balance to be struck between the maximum numbers of items included vs. ease of use. Clearly short questionnaires are of greater benefit in a clinical setting or trial (53,54) where longer scales may be impractical. However, in a research setting scales containing a more comprehensive set of items may yield more information, although the aim should be to reduce the number of items to the minimum required to provide sufficient useful information.

General health measures, which allow comparison between diseases of different specialities, are the most widely used and there are a number available for use in children (53). Specialty-specific and disease-specific questionnaires are often of more use when investigating a specific disease, but may be used in combination with a generic scale. However, for rare diseases disease-specific questionnaires are unlikely to be available (54). It is important that future HRQoL studies concentrate on further validation of existing questionnaires, rather than construction of new ones for the sake of it, except where there is an obvious requirement (13,53). HRQoL is relatively new to paediatric dermatology but there are now a few validated, reliable scales available (13) (Table 1). Currently there are eczema-specific scales for parents (12,15,20) and infants (14) but none for school-age children or teenagers, although there is a combined measure for parents and young children (20) and a dermatology-specific measure for school-age children up to 16 years (9).

Proxy scales, usually completed by parent/carer are used for investigating younger children or those with cognitive defects (55), and when working with children it is important to use scales that are developmentally appropriate and allow completion by proxy (54). Proxy scales can also be used in conjunction with an older child’s response to obtain a more complete overview of HRQoL impairment. Comparison between parental proxy data and the child’s response shows broad agreement between the two but is better correlated for physical rather than psychological parameters (55,56). Beattie and Lewis-Jones (8) demonstrated

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reasonably good agreement between child and parent for total HRQoL score and both gave AD the highest score (indicating greater HRQoL impairment) of common chronic skin diseases.

Health-related quality of life measures for children and their parents have been used successfully in several clinical studies (57–62) demonstrating their apparent ability to detect clinical change. Schiffner et al. (63) reviewed HRQoL measures in the treatment of AD for both adults and children which, apart from a few minor inaccuracies, is a useful overall review.

Utility Studies and Eczema

Utility is a measure of the importance an individual attaches to a particular choice or course of action (64). Generic preference-based QoL measures are increasingly used by health economists to obtain quality-adjusted years (QALYs) but are probably inappropriate for use in younger children with eczema. However, Stevens et al. (65) recently developed a preference-based QoL proxy scale for use in children with AD, which may prove useful. A number of types of scales are available, the simplest of which is a simple 10 cm analogue scale for overall general health expressed as a fraction of 1.0. Comparative data are available for adults for many chronic diseases. Examples of other utility methods include standard gamble techniques and financial or time trade-offs but although these techniques have been used for adults with severe AD (66), there are no data available for children or their parents. A small pilot study published only as an abstract found that children aged 5–8 years ranked pets, or their favourite toy and playing with friends to be most important aspects to them (67). This might be suitable for future use in trade-off utility studies in childhood. A weak correlation was found between the utility index and the Children’s Dermatology Life Quality Index® (CDLQI) score. Lawson et al. (12) used a method of importance ranking of 12 questions using a Multi-Attribute (MAUT) method (64) in parents of children with AD and found that the most important items were the child’s ability to cope with their eczema, practical difficulties of AD care and satisfactory family relationships. In the ISOLATE study the ability to cope with eczema was also rated as the most important factor (36).

SPECIALTY-SPECIFIC MEASURES FOR CHILDREN WITH SKIN DISEASE

The Children’s Dermatology Life Quality Index (CDLQI®)

The CDLQI (9) was the first validated specialty-specific dermatology scale for school-age children published over a decade ago, and has been shown to demonstrate good repeatability and sensitivity to clinical change. The measure, available in 19 different languages, was devised from information obtained from children aged 4–16 years with all types of common skin problems and comprises a simple 10-question scale in written (9) or cartoon form (68), containing domains of physical, social and psychological impact (symptoms and emotions, social relationships, schooling, recreation, sleep and treatment difficulties). It is easy to administer in a clinical or postal setting taking around 2 min to complete (9,68), making it suitable for clinical use or research. Younger children may require parental help or it can be completed as a proxy measure. Questions relate to the last week to allow for accurate recall and answers use a four-part Likert scale. A higher score indicates greater impairment of HRQoL but to try to give meaning to a specific score ‘banding’ of the scores, similar to that recently performed for the adult DLQI (69) is currently underway. A relationship between eczema severity and impairment of HRQoL has been demonstrated (31,47,59,70,71). In a community-based study on eczema Ben-Gashir et al. (71) quantified the sensitivity to clinical change showing that 1 unit of change in the SCORAD (72) (a measurement of eczema severity in children) equated to 0.12 unit change in the CDLQI score.

Use of the CDLQI in children with all types of common skin diseases has demonstrated that those with eczema, scabies and psoriasis have the greatest mean impairment of HRQoL (7–9,70). The highest scoring CDLQI questions in children with eczema are those related to symptoms (itching and soreness), sleep disturbance, problems relating to school and treatment difficulties. The CDLQI has been used in over 35 publications (73) and in AD as an outcome measure in clinical practice (74), in pharmaceutical studies (57,58) and as part of clinical audit (75). A large number of other studies using the CDLQI are currently underway throughout the world.

DISEASE-SPECIFIC SCALES FOR ATOPIC ECZEMA

Infant’s Dermatitis Quality of Life index® [IDQoL]

This is a simple one-page proxy questionnaire, similar in format and scoring to the CDLQI, with 10 questions pertaining to the previous week derived from proxy (parental) information about the impact of AD on a child’s life (14). There is also an additional question, scored independently, on the parent’s perception of global severity over the previous week which allows comparison with the main questionnaire. It is suitable for infants with eczema from birth to 4 years and is currently available in 15 languages (73). There are a number of studies reporting its use (72) and many more are underway. Beattie and Lewis-Jones (76)
recently audited the use of both the IDQoL and the Dermatitis Family Impact (DFI) as routine HRQoL measures in an outpatient setting concluding that they were easy and quick to use, providing valuable additional information on problems faced by the child and their family (76). Both questionnaires were also sensitive to clinical changes in severity as measured by the parent’s global severity rating.

**SCALES TO MEASURE THE IMPACT ON THE FAMILY**

**The Dermatitis Family Impact score**

The original study design for this scale comprised in-depth ethnographic interviews of families with children with AD from all social classes (12). The qualitative data obtained were used to construct a questionnaire containing over 100 items within 11 domains and including 12 utility questions, which provided the quantitative data. The DFI (previously known as the FDI) is a simpler shorter scale derived from this for routine clinical use. The construction is similar to the CDLQI with 10 questions pertaining to the last week. It has now been validated for use in nine languages (73) and shows good repeatability and sensitivity to clinical change (31,33), which has been quantified (33). Cross-validation studies have demonstrated good correlation between the DFI, CDLQI and IDQOL (14,31,33,74,77). The DFI has been used as a clinical outcome measure for episodes of care (78) and in audit (74). It may be used alone or in conjunction with other HRQoL measures for children such as the IDQoL or CDLQI (73) to provide additional data on the impact of AD.

**The Parents Index for Quality of Life in Atopic Dermatitis**

McKenna et al. (15,79) adopted a ‘needs-based’ approach when constructing the Parents’ Index of Life in Atopic Dermatitis (PIQoL-AD). This assesses the negative impact of AD on a range of needs rather than enquiring into parents’ symptoms or ability to function, which has been used in most other studies. This novel 28-item measure has recently been validated simultaneously for use in several European languages as a clinical HRQoL outcome tool (15). A two-point response is used and the time frame is described as ‘at the present moment’. It is suitable for use with parents of children aged 8 years or less with AD and has demonstrated sensitivity to clinical change in clinical trials. Results confirmed the previous findings of the DFI of the large impact of AD on parent’s lives. To date the PIQoL-AD has been used exclusively as an outcome measure for pharmaceutical studies on topical pimecrolimus and in the ISOLATE study (36). Secondary analysis of data from four trials enabled disease severity to be linked to QoL scores indicating that a two to three point change in score could be considered to be clinically meaningful (80). It is suitable for use with other HRQoL outcome measures in childhood atopic eczema, although it may prove more difficult to administer and interpret quickly in an outpatient setting.

**The Childhood Atopic Dermatitis Impact Score® (CADIS)**

This newly validated 45-item scale is unique in that it combines questions about the impact of AD on American children aged 4–8 years and their parents using a five-category choice method (16,20). It was constructed using data from a qualitative study (20), which confirmed the findings of Lawson et al. (12) and McKenna et al. (15) and drew particular attention to the large psychological impact of AD on parents. Itching and scratching, the child’s pain/discomfort and sleep issues were also of particular concern to parents. CADIS appears to have good content and construct validity but it has yet to be used in clinical research.

**COMMENT**

Atopic dermatitis has been shown to have the potential for profound and far-reaching effects on all aspects of the lives of children and their families, particularly in those cases of severe disease. The evolving discipline of HRQoL, whilst still in its infancy, has enabled exploration of these effects in greater detail and has demonstrated the physical, social and psychological problems associated with AD. Although there are now a few suitable validated HRQoL measures available, the lack of original ‘gold standards’ has generally resulted in a failure to cross validate most questionnaires and this should be fuel for further studies. In addition, the clinical meaning of the scores and their relationship to clinical change has yet to be clearly defined. Surprisingly there has been more research into the impact of eczema on parents/families than on the children themselves. Most studies to date have concentrated on proxy data and much more work is required in all age groups of children, particularly teenagers, in order to determine their perspective on the impact of AD. However, such future studies should also ensure that comparative proxy data are obtained from the parent(s) or carers. Much of the current information on AD has come from HRQoL scales developed in ‘western’ cultures mainly of white Caucasian origin and we require information from all ethnic groups. A study from Birmingham examined the effects of AD on HRQoL in three ethnic groups and found significant differences between groups, with higher impairment of HRQoL in Pakistani/ Bangladeshi and Indo-Asian/ Black groups compared with White Caucasian, particularly amongst infants (81). Other aspects that require exploration are gender influences, the effect of social class and education.
and family function (13). When translating scales into other languages it is vital that they retain their original meaning and that they are revalidated for use in that particular culture. Alternatively construction may be undertaken simultaneously in many different countries (15).

The chronic nature of atopic eczema together with its high world prevalence confirms its place as an extremely important childhood disease that has been under-recognised by healthcare analysts in the past despite evidence to suggest an associated high socio-economic burden. Inclusion of HRQoL measures as part of the assessment of AD will provide essential additional information and enable us to argue for appropriate resources for future disease management (13,17).

DECLARATION OF INTEREST

Dr MS Lewis-Jones is co-copyright holder of the CDLQI, IDQoL and DFI.

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