

Instruments that measure the quality of life in atopic dermatitis among children and adolescents

Clin. Invest. (2013) 3(10), 935–942

Atopic dermatitis (AD) continues to be a stigmatizing disease that has a negative impact on the quality of life of patients and their families. Despite increasing knowledge about the disease, its prevalence has been increasing in the last few decades. There has been a significant growth in the number of questionnaires used in the evaluation of quality of life in AD. Consequently, the numbers of clinical trials addressing the topic have also increased. This review will summarize the recent research on AD. The objective of this review is to discuss the contribution of the different instruments used to evaluate quality of life of AD patients, in order that the necessary multidisciplinary approach is instituted routinely in the different health services around the world.

Keywords: adults • atopic dermatitis • Brazil • children • family members
• quality of life • teenagers

The holistic evaluation of patients has been highlighted by many authors from a wide variety of locations. There is a growing number of studies that address the importance of evaluating the patient as a whole. From this holistic point of view, depending on the degree of skin involvement, atopic dermatitis (AD) can be a severely stigmatizing disease, often involving complex personal and social factors that cause patients profound dissatisfaction with their lives. The families of these patients are often deeply involved, not only emotionally, but also physically and financially.

There is growing literary evidence in the form of questionnaires that measure quality of life. They are created with the purpose of measuring the subjective aspects surrounding these diseases and are aimed at the patients and their families.

AD is characterized as a chronic and inflammatory disease. It affects all age groups but is most common in childhood. In 85% of cases, children have symptoms in early childhood, and 50% of them have symptoms in the first year of their life; 45% of children with AD present early respiratory symptoms at 5 years of age [1,2]. Only 16.8% of the patients present symptoms after adolescence [3,4]. Developmental studies have shown that the earlier the onset of clinical manifestations, the more lasting the effects of the disease will be.

AD's prevalence has increased in the last four decades, especially in industrialized countries. Even though the reason for this increase is not fully established, it is believed that environmental factors, such as pollution, exposure to allergens and infections are involved [5]. In addition, genetic factors, immunological, dietary antigens, defects in the skin barrier and many others are thought to be at play. A family history of atopy is a risk factor for the development of atopic diseases. It is estimated that if both parents are allergic, the chance of their children having allergic reactions is approximately 70% [6]. It is often associated with other atopic diseases such as allergic rhinitis and bronchial asthma. That fact reinforces the genetic basis of AD. These are individuals who have a predisposition to excessive synthesis of IgE for specific

Cláudia Soïdo Falcão do Amaral¹,
Maria de Fátima Bazhuni Pombo
March² & Clemax Couto Sant'Anna*²

¹Dermatologic Allergy & Immunology
Department of the Institute of Dermatology,
Ruben David Azulay of Santa Casa of Misericórdia,
Rua Santa Luzia, 206, Centro, Rio de Janeiro, RJ,
Brazil, CEP: 20.020-020

²School of Medicine of Federal University of Rio
de Janeiro, R Bruno Lobo 50, Cidade Universitária,
21941-590, Rio de Janeiro, RJ, Brazil

*Author for correspondence:

Tel.: +55 21 2235 3634

E-mail: clemax01@yahoo.com

FUTURE
SCIENCE

part of

fsg

antigens, especially those that are inhaled [7–9]. Therefore, AD is called a multifactorial disease [10]. Changes in the skin barrier allow the passage of allergens, including aeroallergens that will sensitize the patient and lead to the development of respiratory allergies [11].

The diagnosis of AD is clinical once there are no more specific exams for its diagnosis. Total IgE and specific IgE in general are raised. Prick test is usually positive mainly for aeroallergens; however, these results may present in patients with respiratory allergy only. Therefore, it is generally established by morphology and the typical distribution of the lesions, due to chronic and relapsing character, the presence of itching, and the personal and family history of positive atopy. The Hanifin and Rajka criteria are still used to aid clinical diagnosis of the disease [12].

AD: social & therapeutic aspects

Due to its chronic and relapsing character, AD requires large financial investments, at governmental personal and familial levels [13]. The financial investment required for the treatment of an AD patient is extremely high and families cannot always maintain such high costs. The financial issues include the fact that children often cannot leave their homes, due to the severity of lesions, thus causing frequent school absence. Sleepless nights are also a factor for poor school performance, because children are encumbered by intense itching. With adults the situation is no different; it might at times be worse and can promote absence from work, loss of employment opportunities and interference in social relations.

The treatment of AD includes a number of general measures such as skin hydration, rapid baths, moisturizing soaps and use of light color and cotton clothes. Controlling the environment of the patient with AD is extremely important, especially in the bedroom. Steps such as the lining the patient's mattress and pillows with an impermeable liner, cleaning the house with a damp cloth, and removing rugs or any object that promotes the accumulation of dust, care with stored clothing, reducing the patient's exposure to aeroallergens are all important sensitizing agents. Drug treatment will depend on the stage of the lesions, severity and extent of symptoms, as well as the presence or absence of secondary infections.

Quality of life: the importance of health

In recent decades the scientific community has become interested in the concept of quality of life (QoL) [14]. QoL constitutes one of the main objectives to be reached all over the world and this fact has been promoting the growth of clinical trials. The measures of QoL have countless applications: evaluation of psychosocial aspects, clinical trials, population

studies, economic analysis and so on, which all seek to guarantee better QoL [14].

The objective of clinical trials is to promote, develop and evaluate the effectiveness of new treatments and new therapeutic interventions for different diseases. Actually, these studies have used QoL as an important measure in the patient's overall evaluation. The perception that the individual has of the disease and the interference caused to their life has been taken into greater consideration. In addition to the individual's perception of their health and the cultural context of which they are part, another fundamental factor is their response to treatment, since graduate clinical improvement is part of the QoL study [15,16]. Therefore, with the aging population and the growing number of chronic diseases, the objective is to have a greater focus on improving QoL [14].

In the 1960s, QoL acquired a more subjective aspect and changed the way people perceived their lives. The impact that the disease caused in their daily lives started to be prioritized for the individual's treatment. The concept of QoL has been evolving over time and its use has increased in various fields used to assess the living conditions of human beings.

The WHO was fundamental in stimulating this change of interpretation. In 1995, the WHO defined QoL as "The perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" [17].

The use of instruments for measuring QoL has increased in health services; the practices developed in these services are increasingly adopted by professionals who work with patients with various diseases [18]. With the growing employment of such instruments in the research of new treatment methods and also in the prevention of diseases, the need of standardization of these methods appeared. The concept of QoL started to be used more in healthcare.

With the need to unite the concept of QoL in the context of health, a term was created relating QoL and health. The health-related QoL (HRQOL) brings an analysis of the disease and the cause of the therapeutic evolution in the lifestyle of the patient, in his well-being and psychological balance [19]. Measurement of HRQOL involves quantifying the effects of the disease on the individual and measuring whether the treatment is actually being effective. The concept of QoL encompasses the involvement and the perception of the individual being assessed. In addition to the areas usually covered (physical, psychological, social and functional), it is recommended to include individual perceptions as religiosity, personal beliefs, and so forth, that should also be incorporated into the concept of health [20].

Especially in developed countries, the measurement of HRQOL has increasingly advanced, stimulating the creation of instruments that measure this quality. Chronic diseases have become the major target for the development of such questionnaires, because they promote, in general, negative impact on the lives of patients and their families [21,22].

It is observed that the possibility of the use of QoL as a measure of clinical significance of therapeutic results has been motivating the development of countless studies of new instruments that could measure this quality [23,24].

The QoL questionnaires allow a better evaluation of the impact of the disease, and of the treatment in the daily life of the patients. They can be generic or specific [25–27]. The generic questionnaires are applied in any population, not specifically assessing the impact that a particular disease can cause the population studied. On the other hand, the specific questionnaires are directly related to the disease being studied, as well as the specific population [25]. They evaluate a specific condition and they provide larger capacity of detecting improvement or deterioration of the aspect under investigation [27]. The disadvantage of the specific instruments is that they do not allow the comparison of distinct diseases. However, it can provide important information from a clinical viewpoint [25,28].

Dermatological diseases have been responsible for the preparation of large quantities of QoL questionnaires. It is likely that this fact occurs because the skin is a large and visible organ, therefore depending on the type of injury and the degree of cutaneous involvement it is responsible for elevated emotional impact.

The QoL questionnaires specifically aimed at children have also grown in literature. Depending on the kind or age group of the questionnaire, it can be filled out by the child or by the child's guardian. The cartoon versions are becoming increasingly popular.

QoL in AD

The assessment of QoL in AD is important because it is a disease with a high prevalence in the world population, which generates a lot of investment for its control. It is a disease that, due to the intense itching, promotes insomnia, irritability and discomfort. The care with baths, skin hydration and clothes, often requires dedication. The patient's social life is usually quite affected at school and professional levels, with routine absences and low productivity. The relationship with friends and coworkers is also impaired, as well as holidays and physical activities [29].

Emotional and sexual relationships are compromised due to the appearance of the skin. Usually there is no drop in the quality of life of sexual partners, but patients report that the appearance of eczema in some situations ends up being an impacting factor [30].

The physical, psychological and psychosocial aspects are significantly affected in AD, both with regard to the patient and their family [28]. These aspects are present in adults and children [28]. In some cases, the physical overlap the others [30]. However, mental health and emotional affects are often greater than the actual physical affects, especially in patients who have a severe form of the disease [31–33]. Other dimensions are also highlighted, such as the cognitive and functional impairment, and behavioral cases [34]. These changes are reflected in the QoL of these individuals [35]. Often patients have severe depression due to the skin lesions [36]. The negative impact of the disease within the patient's family is notorious; at times being on the physical, social and emotional level [37]. The family's distress is highest when there is a child with AD. There are restrictions to the social life due to increased work, time and energy devoted to the special needs of a child with eczema, which can lead to exhaustion, sadness and depression [29,38]. A physical and mental health change of mothers caring for children with AD has already been addressed in the literature, as well as the correlation between disease severity and QoL of the family [39,40]. The same way that the child's QoL is affected by the way family relates to the disease, QoL of the family is affected by the disease of the child, especially when it comes to severe cases [34,41].

The orientation and education of atopic patients, combined with psychological treatment of the patients and relatives, are important measures to reduce the negative impact of AD on the QoL as a whole [29]. Listening to the patient and observing the perception that he and his family have of the disease, could also help in choosing the most appropriate therapy, improving doctor–patient relationship and consequently the QoL of people involved [42].

The clinical trials that measured the gravity of the AD did not address the effects on QoL [43]. The interest in this subject has increased over the years, so that today we already have several recognized research publications addressing this concern.

The use of questionnaires measuring QoL, through a predetermined score, has a quantifiable objective of determining the intensity of impairment caused by the disease in these individuals [44]. The regular use of these questionnaires in patient assessments has been suggested by several authors [45–47].

QoL measurement in AD: the questionnaires

Currently, there are numerous surveys in the literature that measure QoL for all kinds of illness. The generic questionnaires that are more commonly used for the evaluation of HRQOL are: NHP (Nottingham Health Profile), SF-36 (36 Items Short Form Health Survey) and SIP (Sickness Impact Profile) [48–51].

One of the generic instruments designed for use in dermatitis in general, most used in AD, is The Children's Dermatology Quality Life Index (CDLQI) [52,53]. It is applied in children and teenagers from 5 to 16 years of age. It should be answered by the patient, where possible, but can also be answered by the patient's guardians. It is composed of ten subjects and six domains relating to the week preceding the interview. The appraised domains are: symptoms and feelings, leisure, school/vacations, personal relationships, rest and treatment. This questionnaire is of English origin. It was validated in the UK and culturally adapted for use in Portuguese (Portuguese as spoken in Brazil) [52]. Recently, the CDLQI was also validated in Brazil [54].

Among the specific questionnaires, the Dermatitis Family Impact Questionnaire (DFI) is one of the most used in the literature [55]. The DFI is a questionnaire of English origin. It was validated in the UK and subsequently translated and culturally adapted for use in Portuguese (Portuguese as spoken in Brazil) [56]. This questionnaire was expanded to be answered by the child's guardians. The objective is to measure the impact of the disease within the context of the family. It is composed of ten questions, all relating to the week prior to the completion of the questionnaire.

These two questionnaires, CDLQI and DFI, have been frequently used in studies of QoL in patients with AD and their families. This is attributed to the easy applicability and to the reliable assessment of the proposed domains [33,57,58].

Regarding the CDLQI questionnaire, the most negatively affected domains are generally those related to symptoms and feelings, itch, sleep disturbance, interference with leisure, personal relationships, school or vacation. The psychosocial aspects are compromised in most cases [59,60].

Studies with the DFI questionnaire show significant impact of the disease on family expenses, tiredness or even exhaustion of parents, as well as family relationships and the quality of sleep and leisure [53,56,61].

A questionnaire used for adults with AD is the Quality of Life Index for Atopic Dermatitis (QoLIAD). It is considered easy to apply and to answer. It contains 25 questions [62–64]. The instrument was developed based on the needs-based model of QoL and was produced in several different countries simultaneously [62]. The initial version of the measure was produced in UK English and translations were produced for The Netherlands, Italy, Germany, France and the USA using a dual translation panel methodology [62].

The Infants Dermatitis Quality of Life Index (IDQOL) is a specific questionnaire. It was designed for use in infants with AD under the age of 4 years, which has been used regularly for the evaluation of the

QoL of patients with this disease. It approaches the following aspects: sleep alterations, humor, difficulties in participating in recreational activities or family life, feeling uncomfortable during bathing, dressing and meals. It is answered by the patients' guardians [65]. In a recent paper, Amaral *et al.* studied the QoL of children and adolescents with AD and the impact of the disease on their families [66]. It used the CDLQI and DFI questionnaires to evaluate QoL, as well as the clinical and socioeconomic variables evaluation. It confirms that this work also showed higher prevalence in females, as is the case in other literary texts [42,67,68]. However, the worst scores (13–30 points) were obtained in males (52.9%), which differed from other articles cited in the literature (Figure 1) [60].

In addition to these data, the descriptive analysis of the sociodemographic variables related to the CDLQI questionnaire showed that there was a significant relationship between gender and the CDLQI ($p = 0.020$) and that the worst scores were found in high-income social classes (52.9%; $p = 0.019$). With regards to the DFI scores on the questionnaire, 30% of parents interviewed were classified into the range of moderate impact on the QoL and 44% in the range that represents the high impact on the QoL, totaling 74% of parents who responded to the questionnaire [66]. These percentages reflect the negative impact of the disease on family life (Figure 2).

There was a significant correlation between the scores of the CDLQI and DFI questionnaires (spearman's rank correlation coefficient $r = 0.635$; $p = 0.0001$; $n = 50$). This correlation shows that the higher the score from the CDLQI, the higher is the expected value of the score of the DFI [66]. The conclusion is that the childhood eczema affects the children and their families' QoL. This result is similar to other authors [58,69–71].

Most recently, an international multicenter study with children from six countries representing three continents was described in the literature. The authors included 419 children with AD and their parents. The aim of the study was to compare the impact of AD on children and their families in different countries. They used two questionnaires: IDQoL and DFI and the conclusion is that these two questionnaires reflect the negative impact that the disease promotes in the interviewed individual's life [72].

Another instrument that has been mentioned in the literature for the children's and the adolescents' evaluation with medical conditions is the Disabkids RA topic Dermatitis Module. It has 12 items answered using a Likert scale, with two versions: self-report (child's version) and proxy version (parent's version) [73].

In general, the literature shows that the use of several questionnaires provides important information

regarding the effects of AD on the lives of patients and their families and demonstrates the usefulness of these measures in routine clinical management of these individuals.

Strategies to improve QoL in AD

It is observed that the patient's life and their family members can be affected in many ways due to the presence of a skin disease, including AD, especially in serious presentation of the condition, which can be stigmatizing. The QoL of the patient and those around him or her has shown worse results when including all of the requirements for the self control of the disease. In some situations, the involvement of the patient with AD can match the effect caused by a systemic disease [74,75].

The use of instruments that measure QoL becomes an effective tool in the evaluation of intervention programs and the need for more research on the social, emotional and behavioral parameters [28].

The routine use of the questionnaires allows a comparison among the scores in different moments of the individual's life. The research performed that use the questionnaires for evaluation of the QoL patients with AD show a correlation of the gravity of the disease with the worst scores. When clinical control occurs, the scores are lower reflecting a better moment of the individual's life. Therefore the routine application of the questionnaires in different stages of the disease and in different consultations has contributed to the patient's daily life. It has been an important partnership in the evaluation of the answer to the treatment and of the QoL [76]. It is possible that these instruments work long term as a demonstration of QoL, allowing the assisting professionals' quicker intervention in the moment the score is higher.

The patient's clinical evolution with AD has been the object of many authors' study and what is of paramount importance of the education is the understanding and the patient's participation in the whole process of his disease. The education should be integrated into the treatment [77,78].

The practice of hydration is a differential in the control of AD, if there is improvement of skin dryness, there is improvement of pruritus [79].

The quality and the best knowledge of the topical and systemic medications have been giving many patients the opportunity to control their symptoms, avoiding further deterioration.

The psychological follow up is mainly necessary in the moderate and severe forms of the disease where pruritus, scratching and problems with sleep are intensive [80]. In the moderate and the severe forms, the disease is stigmatizing and the social reclusion is quite common.

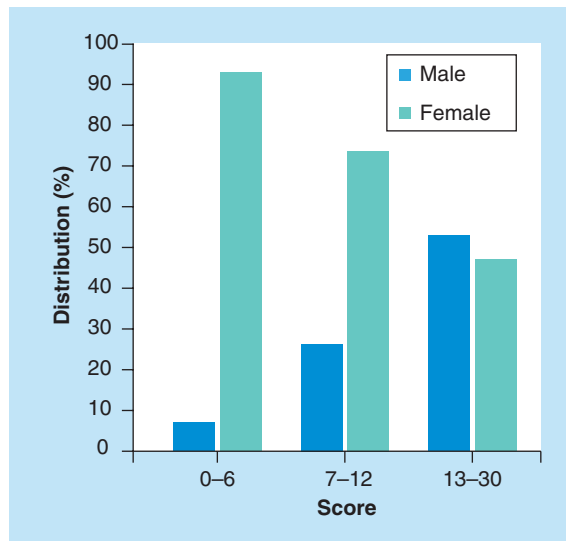


Figure 1. Distribution according to sex and age of the score from The Children's Dermatology Life Quality Index – SCMRJ (Rio de Janeiro, Brazil; n = 50).

Despite the available knowledge of the disease and the therapeutic options available, the satisfactory clinical control is not reached. Perhaps with the improvement of the genetic, immunological and physiological insights into the pathomechanisms of AD we will overcome the limitations of the treatment [81].

One strategy that has been successfully adopted is the formation of support groups for AD. These groups are geared toward patients and their families. The purpose of participation in such groups is to promote multidisciplinary approach. It is usually composed of

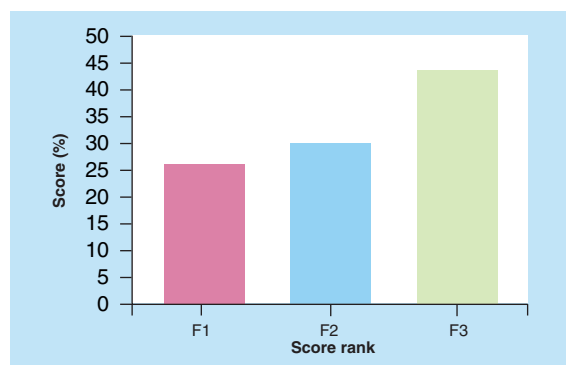


Figure 2. Distribution in the Dermatitis Family Impact Questionnaire SCMRJ (Rio de Janeiro, Brazil [2012]; n = 50). The Dermatitis Family Impact Questionnaire score was divided into three ranks for better statistical analysis: F1: 0–6 points (no or little impact on the atopic dermatitis patient's family's quality of life); F2: 7–12 points (moderate impact on quality of life of the family) and F3: 13–30 points (high impact on the quality of life of the family).

doctors, nurses and psychologists extending in some cases to the participation of social workers and nutritionists. Besides the importance of the multidisciplinary approach highlighted in groups, there is also the opportunity to exchange experiences among patients and parents of those who attend the meetings. It is an opportunity to share the complexity of the disease with other individuals who face similar problems [82].

A group of researchers at the University of Bologna in Italy, set up an educational program for parents of young children with AD. The program consists of six meetings at weekly intervals involving a pediatric allergist, a dermatologist and a psychologist. They observed that the program, in association with conventional treatment, decreased the levels of anxiety of the family and it was able to create more interaction among children, parents and physicians. The result of the program was the improvement of the QoL of the children and their parents [83].

A multidisciplinary approach, participation in support groups and a better understanding of the disease with all aspects surrounding it, make a difference in the patient's adherence and the adhesion of the family too. In fact, there is an improvement of subjective and objective symptoms, there is optimization for treatment adherence and consequently improved QoL [84].

Future perspective

The articles that address QoL in AD, have shown the negative impact that the disease has on a patient's life as well as in their family. Therefore, an evaluation of the QoL is recommended in daily practice through the use of questionnaires and the development of an education program on the disease. The routine use of the QoL questionnaires will give the data to draw the attention of the authorities and maybe even bring about governmental measures to facilitate the patient's access to care and the purchase of medicines.

Disclaimer

Opinions expressed in this article are those of the authors alone, and are not those of any medical society or professional association.

Financial & competing interests disclosure

The authors have no relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript. This includes employment, consultancies, honoraria, stock ownership or options, expert testimony, grants or patents received or pending, or royalties.

No writing assistance was utilized in the production of this manuscript.

Executive summary

- The study of quality of life (QoL) in health has increased in recent years, especially when addressing chronic diseases.
- The dermatological diseases have motivated many studies of QoL and the creation of specific questionnaires to measure and reflect the negative impact of skin diseases in this capacity.
- Atopic dermatitis is a chronic relapsing disease, with varying degrees of skin involvement, a stigmatizing disease with a high degree of impaired QoL of patients and their families. So, it has been one of the skin diseases that has been most prolific in the creation of specific QoL questionnaires.
- The knowledge of patients and their families about the chronic nature and the difficulties inherent to the disease, guidance on the need for frequent monitoring, preventive treatment and control of acute exacerbations has been a differentiator for clinical control.
- The multidisciplinary treatment, especially in relation to the psychological support of the patient and their family and the formation of support groups, which allow multidisciplinary approach beyond the exchange of experiences between patients and their relatives are also a differential in the clinical outcome of these individuals.
- The increasing use of QoL questionnaires has provided statistical data that prove the negative impact that the atopic dermatitis causes in a patient's life and in their family's lives. It accompanies this individual as a whole, including the socioeconomic aspects, due to the high financial investment required for treatment.
- The routine use of the QoL questionnaire at different timepoints during a patient's clinical development, can contribute to the evaluation of their progress during treatment, as well as their deterioration. When the score rises, it allows preemptive intervention in the exacerbations of the disease.
- The statistical data obtained in these studies may be able to encourage government support with measures to facilitate patient access to care and treatment.

References

- 1 Castro APM, Solé D, Filho NAR *et al.* Guia Prático para o Manejo da Dermatite Atópica. Opinião conjunta de especialistas em alergologia da Associação Brasileira de Alergia e Imunopatologia e da Sociedade Brasileira de Pediatria. *Rev. Bras. Alerg. Imunopatol.* 29(6), 268–282 (2006).
- 2 Williams HC, Burney PG, Hay RJ *et al.* The UK Working Party's diagnostic criteria for atopic dermatitis. *Br. J. Dermatol.* 131, 383–396 (1994).
- 3 Williams HC, Strachan DP. The natural history of childhood eczema: observations from the British 1958 birth cohort study. *Br. J. Dermatol.* 139, 834–839 (1998).
- 4 Ozkaya E. Adult-onset atopic dermatitis. *J. Am. Acad. Dermatol.* 52, 579–582 (2005).

- 5 Torres-Borrogo J, Molina-Teran AB, Montes-Mendoza C. Prevalence and associated factors of allergic rhinitis and atopic dermatitis in children. *Allergol. Immunopathol. (Madrid)* 36(2), 90–100 (2008).
- 6 Wandalsen GF, Camelo-Nunes ICC, Naspitz CK, Solé D. Fatores de risco para eczema atópico em escolares. *Rev. Inst. Matern. Infant Pernamb.* 5, 19–25 (2005).
- 7 Williams H. Disease definition and measures of disease frequency. *J. Am. Acad. Dermatol.* 45(Suppl. 1), 33–36 (2001).
- 8 Leite RMS, Leite AAC, Costa IMC. Dermatite atópica: uma doença cutânea ou uma doença sistêmica? A procura de respostas na história da dermatologia. *An. Bras. Dermatol.* 82, 71–78 (2007).
- 9 Zheng T, Yu J, Oh MH, Zhu Z. The atopic march: progression from atopic dermatitis to allergic rhinitis and asthma. *Allergy Asthma Immunol. Res.* 3, 67–73 (2011).
- 10 Leung DY, Soter NA. Cellular and immunologic mechanisms in atopic dermatitis. *J. Am. Acad. Dermatol.* 44(Suppl. 1), S1–S12 (2001).
- 11 Fuiano N, Incorvaia C. The atopy patch test: is it time to redefine its significance? *Ann. Allergy Asthma Immunol.* 106, 278–282 (2011).
- 12 Hanifin JM, Rajka G. Diagnostic features of atopic dermatitis. *Acta Dermatol. Venereol. (Stockholm)* (Suppl. 92), 44–47 (1980).
- 13 Kump AS. Cost of illness of atopic dermatitis in children: a societal perspective. *Pharmacoeconomics* 2, 105–113 (2003).
- 14 Campolina AG, Ciconelli RM. Qualidade de vida e medidas de utilidade: parâmetros clínicos para as tomadas de decisão em saúde. *Rev. Panam. Salud Publica* 19(2), 128–136 (2006).
- 15 Balkrishnan R, Manuel J, Feldman SR, Rapp SR. Measurement of health-related quality of life (HRQOL) associated with skin disease. *J. Am. Acad. Dermatol.* 51, 53–54 (2004).
- 16 Ciconelli RM. Medidas de avaliação de qualidade de vida. *Rev. Bras. Reumatol.* 43, 9–13 (2003).
- 17 The WHOQOL Group. The World Health Organization quality of life assessment (WHOQOL): position paper from the World Health Organization. *Soc. Sci. Med.* 41, 1403–1409 (1995).
- 18 Seidl EMF, Zannon CMLC. Qualidade de vida e saúde: aspectos conceituais e metodológicos. *Cad. Saúde Pública (Rio de Janeiro)* 20(2), 580–588 (2004).
- 19 Hahn EA, Cella D, Chassany O *et al.* Precision of health-related quality-of-life data compared with other clinical measures. *Mayo Clin. Proc.* 82(10), 1244–1254 (2007).
- 20 Oliveira R, Orsini M. Escalas de avaliação de qualidade de vida em pacientes brasileiro-sapós acidente vascular encefálico. *Revista Neurociência* 17, 255–262 (2009).
- 21 Grange A, Bekker H, Noyes J, Langley P. Adequacy of health-related quality of life measures in children under 5 years old: systematic review. *J. Adv. Nurs.* 59, 197–220 (2007).
- 22 Klatchoian DA, Len CA, Terrei MT *et al.* Quality of life of children and adolescents from São Paulo: reliability and validity of the Brazilian version of the Pediatric Quality of Life Inventory TM version 4.0 generic core scales. *J. Pediatr. (Rio de Janeiro)* 84, 308–315 (2008).
- 23 Prebianchi HB. Medidas de qualidade de vida paa crianças: aspectos conceituais e metodológicos. *Psicolteor. Prat.* 5(1), 57–69 (2003).
- 24 Rouse C, Boisauvert B. Quality of life and scales measuring. *R. Méd. Int.* 28, 458–462 (2007).
- 25 Coghi SL. Avaliação da qualidade de vida dos pacientes adultos com dermatite atópica. (MSc thesis). São Paulo: *Faculty of Medicine, Universidade de São Paulo, Brazil* (2005).
- 26 Campos MO, Neto JFR. Qualidade de vida: um instrumento para promoção de saúde. *Rev. Baiana. Saúde Púb.* 32(2), 232–240 (2008).
- 27 Soares AHR, Martins AJ, Lopes MCB *et al.* Qualidade de vida de crianças e adolescentes: uma revisão bibliográfica. *Ciência e Saúde Coletiva* 16(7), 3197–3206 (2011).
- 28 Santos VS. Qualidade de vida em crianças e adolescentes com problemas de saúde: conceptualização, medida e intervenção. *Psicologia, Saúde e Doenças.* 7(1), 89–94 (2006).
- 29 Lewis-Jones S. Quality of life and childhood atopic dermatitis: the misery of living with childhood eczema. *Int. J. Clin. Pract.* 60(8), 984–992 (2006).
- 30 Misery L, Finlay AY, Martin N *et al.* Atopic dermatitis: impact on the quality of life of patients and their partners. *Dermatology* 215(2), 123–129 (2007).
- 31 Mozaffari H, Poupak Z, Pourseyed S *et al.* Quality of life in atopic dermatitis patients. *J. Microbiol. Immunol. Infect.* 40(3), 260–264 (2007).
- 32 Kiebert G, Sorensen SV, Revick D *et al.* Atopic dermatitis is associated with a decrement in health-related quality of life. *Int. J. Dermatol.* 41(3), 151–158 (2002).
- 33 Holm EA, Wulf HC, Stegmann H, Jemec GB. Life quality assessment among patients with atopic eczema. *Br. J. Dermatol.* 154(4), 719–725 (2006).
- 34 Bullinger M, Schmidt S, Peterson C. Assessing quality of life of children with chronic health conditions and disabilities. A European approach. *Intern. J. Rehabilitation Res.* 25, 197–206 (2002).
- 35 Schiffner R, Schiffner-Roche J, Landthaler M, Stolz W. Treatment of atopic dermatitis and impact on quality of life. *Pharmacoeconomics* 21(3), 159–179 (2003).
- 36 Hong J, Koo B, Koo J. The psychosocial and occupational impact of chronic skin disease. *Dermatol. Ther.* 21(1), 54–59 (2008).
- 37 Al Robbae AA, Shahzad M. Impairment quality of life in families of children with atopic dermatitis. *Acta. Dermatovenerol. Croat.* 18(4), 243–247 (2010).
- 38 Warschburger P, Buchholz HT, Petermann F. Psychological adjustment in parents of young children with atopic dermatitis – which factors predict parental quality of life? *Br. J. Dermatol.* 150 (2), 304–311 (2004).
- 39 Ho RC, Giam YC, Ng TP *et al.* The influence of childhood atopic dermatitis on health of mothers and it's impact on Asian families. *Pediatr. Allergy Immunol.* 21(3), 501–507 (2010).
- 40 Balkrishnan R, Housman TS, Carrol C *et al.* Disease severity and associated family impact in childhood atopic dermatitis. *Arch. Dis. Child.* 88(5), 423–427 (2003).
- 41 Boling W. The health of chronically ill children: lessons learned from assessing family caregiver quality of life. *Family Community Health* 28, 176–183 (2005).
- 42 Alvarenga TMM, Caldeira AP. Qualidade de vida em pacientes pediátricos com dermatite atópica. *J. Pediatr. (Rio de Janeiro)* 85(5), 415–420 (2009).
- 43 Charman C, Chambers C, Williams H. Measuring atopic dermatitis severity in randomized controlled clinical trials: what exactly are we measuring? *J. Invest. Dermatol.* 120(6), 932–941 (2003).
- 44 Haliona B, Beumont MG, Lunel F. Quality of life in Dermatology. *Int. J. Dermatol.* 39, 801–806 (2000).
- 45 McKenna SP, Doward LC. Quality of life of children with atopic dermatitis and their families. *Curr. Opin. Allergy Clin. Immunol.* 8(3), 228–231 (2008).
- 46 Weber MB, Lorenzini D, Reinehr CP, Lovato B. Assessment of the quality of life of pediatric patients at a center of excellence of dermatology in southern Brazil. *An. Bras. Dermatol.* 87 (5), 697–702 (2012).

- 47 Neri E, Agostini F, Gremigni P *et al.* Italian validation of the childhood atopic dermatitis. Impact scale: a contribution to its clinical application. *J. Invest. Dermatol.* 132(11), 2534–2543 (2012).
- 48 Teixeira-Salmella LF, Magalhães LC, Souza AC *et al.* Adaptação do Perfil de Saúde de Nottingham: um instrumento simples de avaliação de qualidade de vida. *Cad. Saúde Pública* 20(4), 905–914 (2004).
- 49 Ware JE Jr, Sherbourne CD. The MOS 36 item short-form health survey (SF-36). I. Conceptual framework and item selection. *Med. Care* 30, 473–483 (1992).
- 50 Ciconelli RM, Ferraz MB, Santos W *et al.* Tradução para a língua portuguesa e validação do questionário genérico de avaliação de qualidade de vida SF-36 (Brasil SF 36). *Rev. Bras. Reumatol.* 39(3), 143–150 (1999).
- 51 Bergner M, Bobbitt RA, Carter WB, Gilson BS. The sickness impact profile: development and final revision of a health status measure. *Med. Care* 19, 787–805 (1981).
- 52 Lewis-Jones MS, Finlay AY. The Children's Dermatology Life Quality Index (CDLQI). Initial validation and practical use. *Br. J. Dermatol.* 132, 942–949 (1995).
- 53 Chernyshov PV. Dermatological quality of life instruments in children. *G. Ital. Dermatol. Venereol.* 148(3), 277–285 (2013).
- 54 Prati C, Comparin C, Boza JC, Cestari TF. Validação para o português falado no Brasil do instrumento Escore da Qualidade de Vida na Dermatologia Infantil (CDLQI). *Med. Cutan. Iber. Lat. Am.* 38, 229–233 (2010).
- 55 Dodington SR, Barsa MK, Finlay AY, Salek MS. The Dermatitis Family Impact Questionnaire: a review of its measurement properties and clinical application. *Br. J. Dermatol.* 169(1), 31–46 (2013).
- 56 Lawson B, Lewis-Jones MS, Finlay AY *et al.* The family impact of childhood atopic dermatitis: the dermatitis family impact questionnaire. *Br. J. Dermatol.* 138, 107–113 (1998).
- 57 Kim DH, Li K, Seo SJ *et al.* Quality of life and disease severity are correlated in patients with atopic dermatitis. *J. Korean Med. Sci.* 27(11), 1327–1332 (2012).
- 58 Monti F, Agostini F, Gobbi F *et al.* Quality of life measures in Italian children with atopic dermatitis and their families. *Ital. J. Pediatr.* 22, 37–59 (2011).
- 59 Brenninkmeijer EE, Legierse CM, Sillevs-Smith JH *et al.* The course of life of patients with childhood atopic dermatitis. *Pediatr. Dermatol.* 26(1), 14–22 (2009).
- 60 Hon KL, Leung TF, Wong KY *et al.* Does age or gender influence quality of life in children with atopic dermatitis? *Clin. Exp. Dermatol.* 35(2), 193–194 (2010).
- 61 Jiráková A, Vojáčková N, Göpfertová D, Hercogová J. A comparative study of the impairment of quality of life in Czech children with atopic dermatitis of different age groups and their families. *Int. J. Dermatol.* 51(6), 688–692 (2012).
- 62 Whalley D, McKenna SP, Dewar AL *et al.* Epidemiology and Health Services Research. A new instrument for assessing quality of life in atopic dermatitis: international development of The Quality of Life Index for Atopic Dermatitis (QoLIAD). *Br. J. Dermatol.* 150(2), 274–283 (2004).
- 63 McKenna SP, Doward LC, Niero M, Erdman R. Development of needs-based quality of life instruments. *Value Health* 7(Suppl. 1), S17–S21 (2004).
- 64 Lambert J, Bostoen J, Geusens B *et al.* A novel multidisciplinary educational programme for patients with chronic skin diseases: Ghent pilot project and first results. *Arch. Dermatol. Res.* 303(1), 57–63 (2011).
- 65 Lewis-Jones MS, Finlay AY, Dykes PJ. The infant's Dermatitis Quality of Life Index. *Br. J. Dermatol.* 144, 104–110 (2001).
- 66 Amaral CSF, March MFBP, Sant'Anna CC. Qualidade de vida das crianças e adolescentes com dermatite atópica. *An. Bras. Dermatol.* 87(5), 717–723 (2012).
- 67 Peters AS, Kellberger J, Vogelberg C *et al.* Prediction of the incidence, recurrence, and persistence of atopic dermatitis in adolescence: a prospective cohort study. *J. Allergy Clin. Immunol.* 126, 590–595 (2010).
- 68 Borges WG, Burns DAR, Guimarães FATM *et al.* Dermatite atópica em adolescentes do Distrito Federal. Comparação entre as fases I e III do ISAAC, de acordo com a situação socioeconômica. *Rev. Bras. Alergia Imunopatol.* 31(4), 146–150 (2008).
- 69 Ganemo A, Svensson A, Lindberg M, Wahlgren CF. Quality of life in Swedish children with eczema. *Acta Dermatol. Venereol.* 87(4), 345–349 (2007).
- 70 Al Shobaili HA. The impact of childhood atopic dermatitis on the patient's family. *Pediatr. Dermatol.* 27(6), 618–623 (2010).
- 71 Al Robbaee AA. Reliability and validity of the Arabic version of 'dermatitis family impact questionnaire' in children with atopic dermatitis. *Int. J. Dermatol.* 49(9), 1063–1067 (2010).
- 72 Chernyshov PV, Jirakova A, Ho RC *et al.* An international multicenter study on quality of life and family quality of life in children with atopic dermatitis. *Indian J. Dermatol. Venereol. Leprol.* 79(1), 52–58 (2013).
- 73 Deon KC, Dos Santos DM, Reis RA *et al.* Translation and cultural adaptation of the Brazilian version of Disabkids® Atopic Dermatitis Module (ADM). *Rev. Esc. Enferm. USP* 45(2), 450–457 (2011).
- 74 Finlay AY. Quality of life indices. *Indian J. Dermatol. Venereol. Leprol.* 70, 143–148 (2004).
- 75 Leite RMS, Leite AAC, Costa IMC. Dermatite atópica: uma doença cutânea ou uma doença sistêmica? A procura de respostas na história da Dermatologia. *An. Bras. Dermatol.* 82(1), 71–78 (2007).
- 76 Higaki Y, Kawamoto K, Kamo T *et al.* Measurement of the impact of atopic dermatitis on patient's quality of life: a cross sectional and longitudinal questionnaire study using the Japanese version of Skindex-16. *J. Dermatol.* 31(12), 977–982 (2004).
- 77 Stalder JF, Bernier C, Ball A *et al.* Therapeutic patient education in atopic dermatitis: worldwide experiences. *Pediatr. Dermatol.* 30(3), 329–334 (2013).
- 78 De Bes J, Legierse CM, Prinsen CA, de Corte J. Patient education in chronic skin diseases: a systematic review. *Acta Derm. Venereol.* 91(1), 12–70 (2011).
- 79 Gelmetti C, Boralev F, Seité S *et al.* Quality of life of parents living with a child suffering from atopic dermatitis before and after a 3-month treatment with an emollient. *Pediatr. Dermatol.* 29(6), 714–718 (2012).
- 80 Kelsay K, Klimmert M, Bender B. Addressing psychosocial aspects of atopic dermatitis. *Immunol. Allergy Clin. North Am.* 30(3), 385–396 (2010).
- 81 Katoh N. Future perspectives in the treatment of atopic dermatitis. *J. Dermatol.* 36(7), 367–376 (2009).
- 82 Takaoka R, Aoki V, Campos TCC. Support groups for patients with atopic dermatitis: a nine-year experience. *Dermatol. Psychosom.* 1, 33–38 (2000).
- 83 Ricci G, Bendandi B, Aiazzi R *et al.* Three years of Italian experience of an educational program for parents of young children affected by atopic dermatitis: improving Knowledge produces lower anxiety levels in parents of children with atopic dermatitis. *Pediatr. Dermatol.* 26(1), 1–5 (2009).
- 84 Staab D, Diepgen TL, Fartasch M *et al.* Age related, structured educational programmes for the management of atopic dermatitis in children and adolescents: multicentre, randomised controlled trial. *BMJ* 332, 933–938 (2006).