

Assessing the Impact of Atopic Dermatitis on the Patients' Parents with the Visual Instrument 'Caregiver-PRISM'

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Key Words

Burden of disease · Caregiver · Suffering · Chronic disease

Abstract

Background: There is a need to improve the quality of communication between clinicians and parents of young patients with atopic eczema (AE). **Objective:** To create a tool to measure the suffering that caregivers experience in association with their child's AE (Caregiver Pictorial Representation of Illness and Self-Measure, Caregiver-PRISM), assess the validity and reliability, and identify factors associated with caregiver suffering. **Methods:** Caregiver-PRISM was administered to 45 parents of patients from an AE outpatient service (Padua, Italy). **Results:** Caregiver-PRISM had a good test-retest reliability ($r = 0.85$; $t_7 = 4.13$; $p < 0.05$), content validity and construct validity when used in parents of AE children. Parents with a less positive family affective climate, higher education, or with children following a diet experienced

higher suffering associated with their child's AE, demonstrated by lower Caregiver-PRISM scores ($p < 0.05$). **Conclusion:** Our results support the use of Caregiver-PRISM in parents of AE patients to assess suffering associated with patients' illness.

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Background

Atopic eczema (AE) is a common, chronically relapsing, pruritic skin disease affecting mainly children and adolescents [1], which affects the quality of life of patients and their families [2, 3]. Mothers of children with AE are more depressive, hopeless, anxious, and

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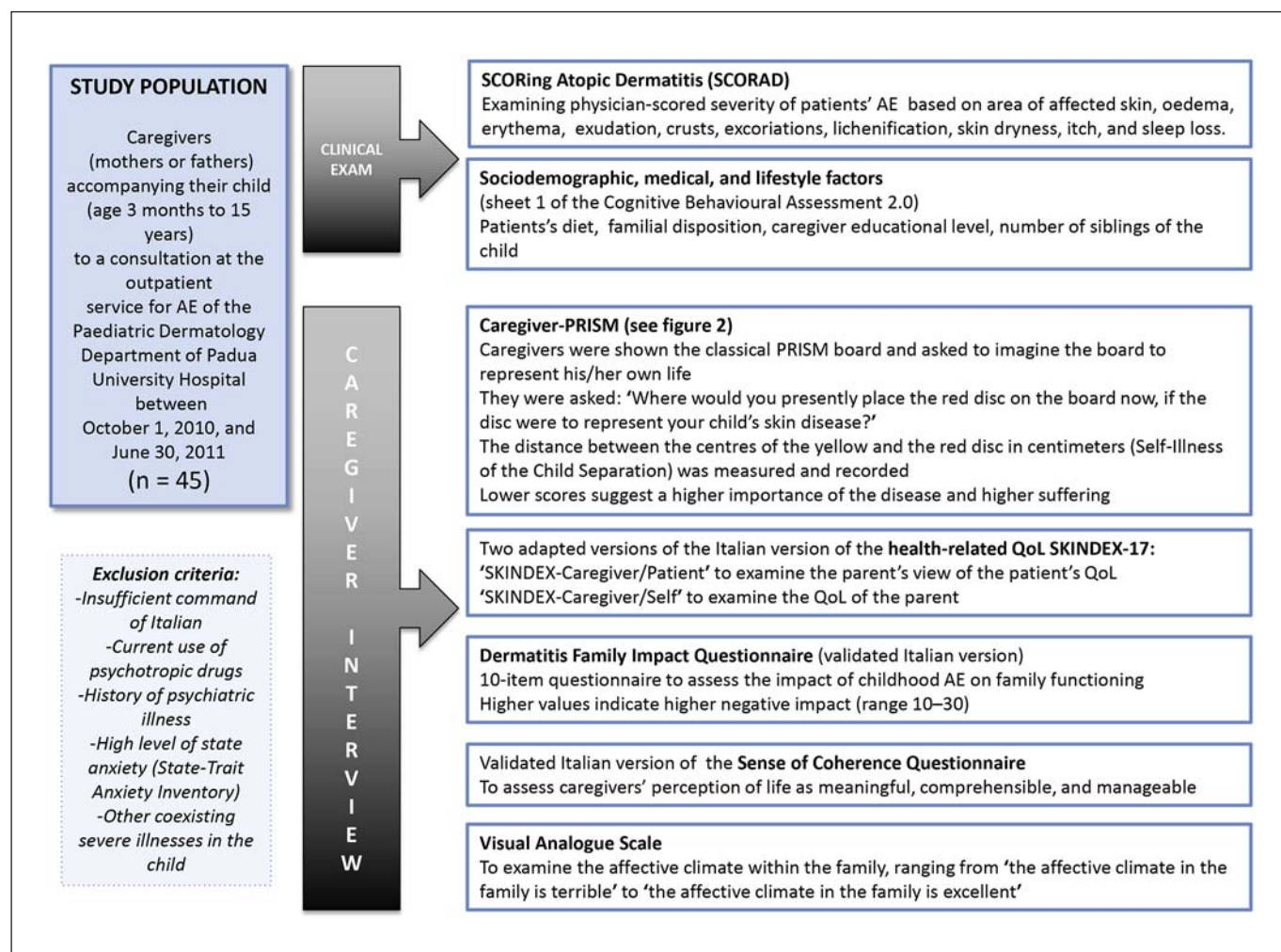


Fig. 1. Flow chart of the Methods.

overprotective than controls [2, 4]. As AE impairs the quality of life of patients' parents [5], it is reasonable to assume that AE might also cause considerable psychological suffering to the parents. Multiple barriers limit communication between caregivers and physicians [6, 7]. A good understanding by the treating physician of the suffering of the parents may conduce to a better physician-parent relationship and, ultimately, increase adherence to treatments and improve efficacy of chosen therapies.

The Pictorial Representation of Illness and Self-Measure (PRISM) is a visual instrument used during clinical interviews [8–11], which allows quantitative assessment of illness-related suffering and is considered to facilitate doctor-patient communication and verbalization of 'difficult-to-externalize' issues. Suffering is a complex con-

cept, with various definitions [12], which has been measured by PRISM in a range of diseases [13–17], including psoriasis [17]. However, most studies on PRISM measure suffering induced in patients by diseases or circumstances affecting the patients themselves [18–21]. Due to cognitive development, the PRISM tool is too abstract to be used directly in children [22]. A similar tool for assessing the level of suffering that parents of children with certain disorders experience could play a similar role in medical consultations, and there is a need to develop and validate such a tool in clinical practice.

We are unaware of any study measuring suffering in parents associated with their child's chronic illness, or specifically in dermatology. Our study aimed to measure suffering in parents induced by their child's AE. A second aim was to obtain a preliminary assessment of which clin-

ical and sociodemographic factors were associated with a higher degree of suffering in parents, including the clinical severity of disease and diet being followed in the patients [23, 24], the number of children in the family, familiarity for AE, and caregiver trait anxiety, sense of coherence, education, age, and sex.

Methods

For further details, see the supplementary materials (for all online suppl. material, see www.karger.com/doi/10.1159/000448030) [8, 25–37] (fig. 1).

Results

Patients included 23 males and 22 females; the parents comprised 39 mothers and 6 fathers. We did not find significant differences in the outcomes between the sex of the parents. The average age of the patients was 74.5 months (SD = 51.1; median = 66, range = 3–180). The average disease severity SCORAD score was 32.20 (SD = 13.70). State-Trait Anxiety (STAI)-State scores were 35.3 (± 8.0) for fathers, and 36.8 (± 7.3) for mothers. The highest STAI-State score was 54; thus, no one had a clinically significant state of anxiety that would warrant exclusion from the study. One individual refused to complete the two STAI questionnaires due to perceived boredom.

There were no other missing data. The mean Caregiver-PRISM score was 86.0 (SD = 70.7; range = 2–253). The distribution of the Self/Illness of the Child Separation (SICS) score was not statistically different from the Gaussian one (KS-Z = 1.315; n.s.), but it was skewed to the left.

Reliability

There was a good test-retest reliability ($r = 0.85$; $t_7 = 4.13$; $p < 0.05$). The difference between the test and retest Caregiver-PRISM scores did not differ significantly ($t_8 = 0.438$; $p = 0.61$).

Content Validity

Three core issues for the Caregiver-PRISM emerged: intrusiveness, lack of controllability, and interference with daily activities, as reported previously for PRISM in adults [10].

Construct Validity

Correlation coefficients for Caregiver-PRISM by Dermatitis Family Impact Questionnaire, SKINDEX-Caregiver/Patient and SKINDEX-Caregiver/Self are displayed in table 1. Convergent validity was confirmed by a statistically significant correlation between Caregiver-PRISM and Dermatitis Family Impact Questionnaire (fig. 2), while divergent validity was confirmed by statistically significant correlations between Caregiver-PRISM and both SKINDEX-Caregiver/Patient and SKINDEX-Caregiver/Self (table 2; fig. 3).

Table 1. Pearson's correlation coefficients between the Dermatitis Family Impact Questionnaire and the two adapted versions of the SKINDEX-17

Instrument	Dermatitis Family Impact Questionnaire	SKINDEX-Caregiver/Patient	SKINDEX-Caregiver/Self
Dermatitis Family Impact Questionnaire	1		
SKINDEX-Caregiver/Patient	0.30*	1	
SKINDEX-Caregiver/Self	0.43*	0.54*	1

* $p < 0.05$.

Table 2. Pearson's correlation coefficients between Caregiver-PRISM and the two adapted versions of the SKINDEX-17

Instrument	Dermatitis Family Impact Questionnaire	SKINDEX-Caregiver/Patient	SKINDEX-Caregiver/Self
Caregiver-PRISM	-0.31*	-0.51*	-0.39*

* $p < 0.05$.

Caregiver-PRISM did not correlate with SCORAD ($r = -0.23$; $t_{43} = -1.52$; $p = 0.13$), STAI-Trait ($r = -0.21$; $t_{43} = -1.42$; $p = 0.15$), or sense of coherence ($r = -0.001$; $t_{43} = 0.004$; $p = 0.97$). Parents whose child followed a diet had lower SICS scores ($t_{43} = -2.81$; $p < 0.05$). Parents with higher educational level had lower SICS scores ($t_{36, 84} = -2.17$; $p < 0.05$). No significant differences were found in SICS scores for age or sex of the patient/child, age or sex of caregiver/parent, single parent families, familiarity for

AE, and number of children at home. The quality of family affective climate correlated positively with the SICS ($r = 0.34$; $t_{43} = 2.35$; $p < 0.05$).

Discussion

Our results show that Caregiver-PRISM has good test-retest reliability, content validity, and construct validity when used in parents of children with AE. Parents with a less positive family affective climate, higher educational level, or with children following a diet seem to experience higher suffering associated with their child's AE, demonstrated by lower SICS scores. Our results provide reasonable evidence for the applicability of PRISM in caregivers of AE patients.

We did not find a strong correlation between Caregiver-PRISM and sense of coherence, contrary to previous results [38]. A low sense of coherence implies the incapability of finding sense in life and hence induction of suffering. PRISM is considered to provide a general measure of suffering, but it is possible that the suffering induced by the illness of a child is of a different nature than the one elicited by one's own ailing. In the former case such suffering may be induced more by empathic responses rather than by experiencing feelings such as loss of meaning. This is supported by the fact that the majority of parents examined were mothers, who might experience greater levels of empathy. Our study identifies the need for further research in this area, to assess different forms of psychological suffering, and whether these forms have even different physiological correlates, such as the activation of mirror neurons in the case of empathic suffering.

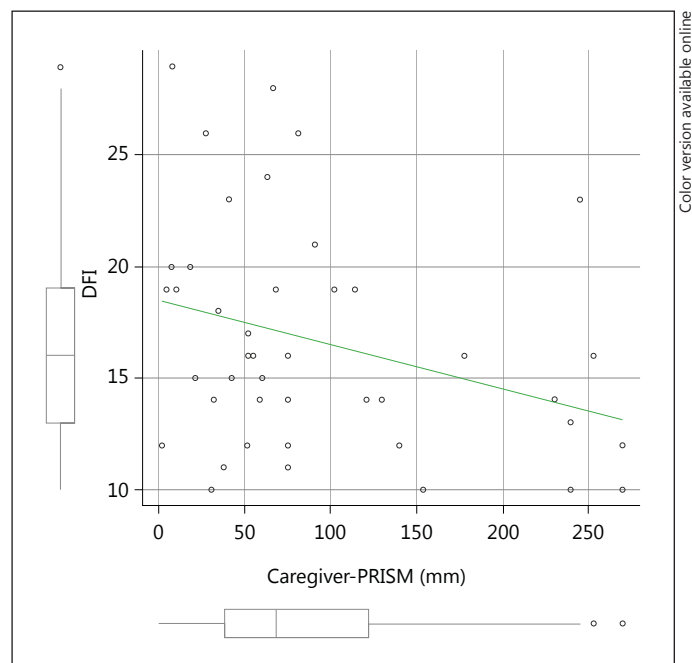


Fig. 2. Caregiver-PRISM plotted against the Dermatitis Family Impact Questionnaire (DFI).

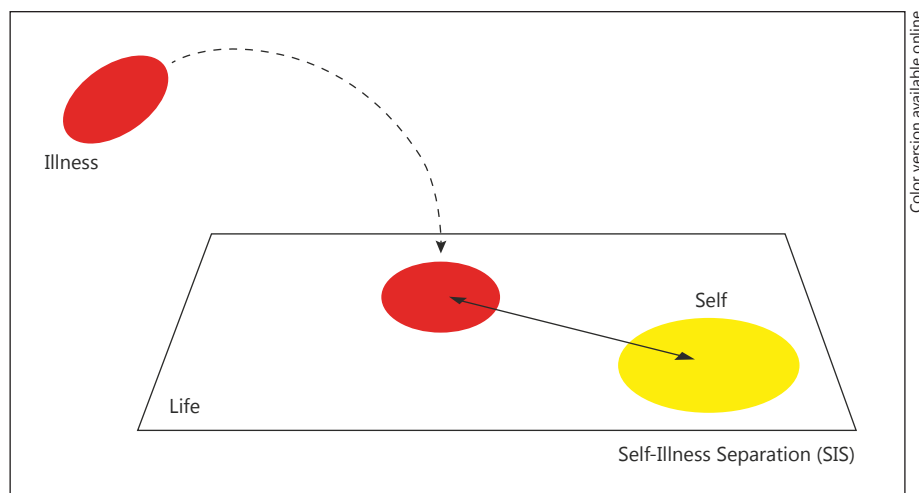


Fig. 3. The PRISM task.

A positive familiar affective climate was associated with caregivers experiencing less suffering in association with their child's AE. Many problems raised by the illness might be better shared among family members. In contrast, the presence of a diet in the patient was associated with higher suffering in parents. Whether and when a diet may help in AE is a highly debated issue between paediatricians and dermatologists [39]. The uncertainty related to this question is likely to increase the parents' suffering. It might also be that preparing food and monitoring the diet of the child itself increases the burden that the parents feel because it affects day-to-day life and requires time, effort, and attention to follow. A higher degree of education in the caregiver was also associated with more suffering. One could hypothesize that highly educated parents will be more aware of the fact that a complete resolution of the symptoms of AE by medical therapy is unlikely. We did not find a correlation between Caregiver-PRISM and the clinical severity of AE. This may be due to the small sample size, or the fact that the nature of AE is well known to parents and they may be fully aware of the heterogeneity of clinical improvements. In a previous study, higher clinical severity was found to be associated with a decrease in quality of life of the family [40].

Caregiver-PRISM might be applicable in different clinical settings, such as for partners or other caregivers of chronically ill patients requiring intense psychological and physical support, e.g. degenerative mental illnesses. More generally, any population of caregivers of patients with severe chronic diseases may be a potential target for the use of Caregiver-PRISM in clinical settings.

The present study has several limitations. First, we used the SKINDEX (SKINDEX-Caregiver/Self) in a manner which, to date, has not been validated. However, it is intuitive that data provided by SKINDEX-Caregiver/Self may support the construct validity of Caregiver-PRISM. The evidence provided using SKINDEX-Caregiver/Self in the validation of Caregiver-PRISM is therefore limited. Second, the brief time interval and the small number of participants may have affected the test-retest reliability. However, it would have been ethically unacceptable not to provide the appropriate dermatological treatment immediately after the first medical interview, and since the treatment was inevitably bound to affect the test-retest outcomes, the choice of timing in our test procedure is likely to be the best possible one. Third, we did not perform measurements concerning a possible sensitivity to change, which needs to be tested on larger samples. Our data was cross-sectional data, and thus we cannot investigate the causality of the associations. Further, we were

unable to investigate directly whether Caregiver-PRISM is able to facilitate good communication between caregivers and paediatricians.

A major limitation of our study was the small sample size. We cannot make any strong conclusions based on our data, but our results highlight the potential usefulness of this test in paediatric patients and the need for more research on this tool in larger samples and different age ranges. Due to the age range of children, it is possible that the impact on caregivers might differ depending on whether the child is an adolescent or a younger child. We stratified our sample into two age groups and found that the results remained unchanged (data not shown). However, due to the small number of adolescents in our sample ($n = 10$), we cannot draw any firm conclusions and suggest that future research examines the potential differential impact on parents of adolescents versus younger children.

A review highlighted the relevance of burden in caregivers of chronically ill patients, suggesting that physicians have a responsibility to recognize such a burden [41]. The assessment of parents' psychological state should ideally be part of routine diagnostic procedures when dealing with chronically ill children, especially as it has been shown to influence inflammatory markers in the child [42, 43] and, therefore, is a relevant factor to consider when treating a child with a chronic inflammatory disease. A comprehensive understanding of the dynamics within the family and of the burden that a child's disease has on caregivers is likely to be conducive to more appropriate decisions by the clinician regarding therapy. Further, it might be associated with better treatment adherence by the patient and their caregiver, resulting in better clinical outcomes. Our study suggests that Caregiver-PRISM may be a useful instrument to achieve this goal. Being a visual instrument to be used during the clinical interview, Caregiver-PRISM is also likely to foster communication between paediatricians and caregivers. Further studies are needed to support this assumption.

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Statement of Ethics

All parents provided written, informed consent before the start of data collection.

Disclosure Statement

The authors have no conflicts of interest and no funding sources to declare.

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