

# The Pictorial Representation of Illness and Self Measure (PRISM) Instrument Reveals a High Burden of Suffering in Patients With Chronic Urticaria

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## ■ Abstract

**Background:** Chronic urticaria severely affects quality of life. To date, no gold standard has been established to measure the burden of suffering, which often correlates poorly with the skin symptoms observed in patients with chronic urticaria.

**Objective:** To investigate the effect of psychological factors on the course of urticaria.

**Methods:** Health-related quality of life was assessed in 95 patients with chronic urticaria using the following instruments: Pictorial Representation of Illness and Self Measure (PRISM), Dermatology Life Quality Index (DLQI), and Skindex-29. Correlations were calculated. Cognitive flexibility and its correlation with the course of urticaria were assessed. Two case reports are presented to further elucidate features of PRISM.

**Results:** PRISM revealed a high burden of suffering that was consistent with considerably impaired quality of life as measured by DLQI and Skindex-29 in the same patients. However, no significant correlation was observed between PRISM and the 2 quality of life questionnaires. From the baseline visit to the follow-up visit, quality of life scores improved significantly (DLQI,  $P=.001$ ; Skindex-29,  $P=.001$ ), whereas the PRISM score remained unchanged ( $P=.085$ ). Disease course was favorable more often in cognitively flexible patients ( $n=54$ ) (91%) than cognitively inflexible patients ( $P=.007$ ).

**Conclusions:** PRISM revealed a high burden of suffering in chronic urticaria and provided helpful additional information for the management of these patients. In our cohort, cognitive flexibility was a positive predictive marker for the course of chronic urticaria.

**Key words:** DLQI. PRISM. Quality of life. Skindex-29. Urticaria.

## ■ Resumen

**Antecedentes:** La urticaria crónica afecta gravemente a la calidad de vida. Hasta la fecha, no se ha establecido un método de referencia para medir la carga de sufrimiento que suele estar poco relacionada con los síntomas cutáneos observados en pacientes con urticaria crónica.

**Objetivo:** Estudiar el efecto de factores psicológicos sobre la evolución de la urticaria.

**Métodos:** Se evaluó repetidas veces la calidad de vida relacionada con la salud en 95 pacientes con urticaria crónica mediante los instrumentos siguientes: *Pictorial Representation of Illness and Self Measure* (PRISM), Índice de calidad de vida en dermatología (DLQI) y el cuestionario Skindex-29. Se calcularon las correlaciones. Se evaluaron la flexibilidad cognitiva y su correlación con la evolución de la urticaria. Se presentan dos casos clínicos para demostrar mejor las características del PRISM.

**Resultados:** El PRISM reveló una carga elevada de sufrimiento en consonancia con una calidad de vida considerablemente afectada determinada mediante los cuestionarios DLQI y Skindex-29 en los mismos pacientes. No obstante, no se observó una correlación significativa entre el PRISM y los 2 cuestionarios de calidad de vida. Desde la visita inicial hasta la de seguimiento, las puntuaciones de calidad de vida mejoraron significativamente (DLQI,  $p=0,001$ ; Skindex-29,  $p=0,001$ ), mientras que la puntuación del PRISM se mantuvo igual ( $p =$

0,085). Los pacientes con un perfil cognitivo flexible (n=54) presentaron con mayor frecuencia una evolución favorable de la enfermedad (91%) que los pacientes con un perfil cognitivo rígido ( $p=0,007$ ).

**Conclusiones:** El PRISM reveló una alta carga de sufrimiento en la urticaria crónica y proporcionó información adicional útil para el tratamiento de estos pacientes. En la cohorte estudiada, la flexibilidad cognitiva fue un marcador predictivo positivo de la evolución de la urticaria crónica.

**Palabras clave:** DLQI. PRISM. Calidad de vida. Skindex-29. Urticaria.

## Introduction

Chronic urticaria is a common skin disease that is characterized by spontaneous itchy wheals. It affects 0.5%-1% of the general population, with an average age of 41 years [1]. If physical urticaria and urticarial vasculitis are not taken into consideration, autoimmune chronic urticaria accounts for 45% of cases and idiopathic chronic urticaria for 55% [2]. Defined as urticaria symptoms every day or on most days for more than 6 weeks, chronic urticaria has a considerable impact on patients' lives [3,4]. Several validated dermatology-specific health-related quality of life questionnaires are available. The best known are the Dermatology Life Quality Index (DLQI), developed by Finlay et al [5], and Skindex-29, developed by Chren et al [6]. However, few instruments assess burden of suffering in patients with chronic urticaria. A novel tool to assess suffering—the Pictorial Representation of Illness and Self-Measure (PRISM) [7]—has been developed and validated in dermatological inpatients [8].

Chronically ill patients may have a reduced ability to perceive and express differences in the symptoms and impact of their disease [9], and this reduced ability can be understood as a neurophysiological correlate of the so called chronicity associated with poor outcomes [10]. PRISM has been shown to assess the ability to perceive and express relevant differences in the impact of a disease. This ability is known as cognitive flexibility [11].

The aim of this study was to validate PRISM, a nonverbal visualization technique to assess the burden of suffering in patients with chronic urticaria, and to compare it with the self-administered quality of life questionnaires DLQI and Skindex-29. Furthermore, we investigated whether cognitive flexibility, as assessed by PRISM during the first visit, had an impact on the course of chronic urticaria. Our hypothesis was that cognitively flexible patients might have a better outcome than cognitively inflexible patients.

## Material and Methods

### Patient Characteristics

A specialty clinic for urticaria patients was established at the Department of Dermatology of the University Hospital of Zurich. From January 2007 to January 2008 all eligible patients suffering from chronic urticaria were prospectively recruited and monitored over a period of 4 months. Chronic urticaria was defined according to the guidelines of the European Academy of

Allergy and Clinical Immunology, the Global Allergy and Asthma European Network, and the European Dermatology Forum [4]. Patients with acute urticaria or other skin diseases and patients younger than 12 years were excluded. Five patients (5.3%) had physical urticaria (2 with cold urticaria, 2 with pressure urticaria, and 1 with friction urticaria). The local ethics committee approved the study protocol (reference number EK 705) and all patients gave their written informed consent to participate. Patients were questioned about their clinical symptoms. Impairment of quality of life was assessed using the DLQI and Skindex-29; burden of suffering was assessed using PRISM at the first visit and at a follow-up visit after 4 months.

### The PRISM Task

PRISM has been validated to measure burden of suffering in a variety of chronic diseases [8,12,13] and was applied in this study as described elsewhere [7,14]. Briefly, the patient is shown a white A4-sized metal board with a fixed yellow disk (representing the patient's self) at the bottom right-hand corner and asked to imagine that the board represents his/her life as it is at the time. The patient is then handed a red disk, asked to imagine that this represents his/her illness, and then asked 2 questions—1) *Where in your life (board) would you place the urticaria disk at the moment?* and 2) *Where would you place the urticaria disk in regard to the last 2 weeks?*—to reflect the importance of the illness in his/her life. The main quantitative measure derived from PRISM is the Self-Illness Separation (SIS), namely, the distance in millimeters—between the centers of the illness and the self disks. The possible range for the SIS is 0-273 mm, with smaller values representing greater suffering (Figure 1).

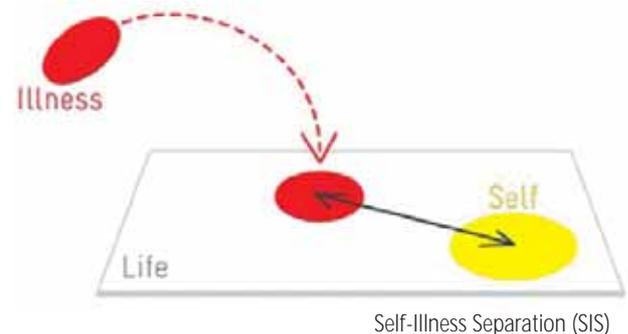


Figure 1. The PRISM task (see Material and Methods). DLQI indicates Dermatology Life Quality Index; PRISM, Pictorial Representation of Illness and Self Measure.

PRISM has been shown to sensitively assess treatment effects in chronic disease [14] and to have the capacity to assess differences in a patient's cognitive flexibility [11], defined in this study as a variation in SIS between questions (i) and (ii) greater than 10%. Patients were rated *flexible*, worse if SIS at the first visit was more than 10% smaller for question 1 than for question 2, *inflexible* if PRISM values differed no more than 10% between questions 1 and 2, or *flexible*, better if PRISM yielded more than 10% better values for question 1.

Patients assessed the clinical outcome of urticaria using written charts in which they recorded presence or absence of urticaria daily during the study. *Improvement* was defined as a reduction of at least 25% in the number of days with urticaria symptoms during the month before the 4-month follow-up visit. Patients with an improvement of less than 25% or deterioration of urticaria were classed as *unimproved*.

### Dermatology Life Quality Index

Originally developed for patients with psoriasis, the DLQI is a simple and validated 10-item questionnaire designed to measure and compare disability arising from several skin conditions [5]. It is used as an assessment tool in daily clinical practice [15,16]. Patients used the DLQI to indicate, on a scale from 0 to 3 for each of the 10 items, how their skin condition influenced quality of life at the time of the assessment and the week before. The total score ranges from 0 to 30: the higher the score, the greater the disability.

### Skindex-29

Quality of life was also assessed using Skindex-29, a validated 29-item instrument to measure the effects of skin diseases on quality of life [6,17]. Results are reported in 3 areas affecting quality of life: emotions, symptoms, and functioning. A composite score (average scale score) was calculated to measure overall impact on quality of life. Higher Skindex-29 scores indicate greater effects on quality of life.

All patients were assessed by the same investigator and completed the PRISM task, DLQI, and Skindex-29 in the urticaria specialty clinic at their first visit and at the follow-up visit.

Two case reports are presented to demonstrate the diagnostic and therapeutic importance of PRISM.

### Statistical Analysis

Data were analyzed using SPSS 11.5 (SPSS Inc., Chicago, Illinois, USA). PRISM, DLQI, and Skindex-29 scores at the first visit and follow-up visit were expressed as absolute mean (SD) and as percentage mean (SD) of maximum scores. Correlations between PRISM, DLQI, and Skindex-29 were expressed using the Spearman rank correlation coefficient ( $\rho$ ). Changes in PRISM, DLQI, and Skindex-29 scores between the first and follow-up visits were expressed as the Cohen

effect size ( $d$ ) (difference in the mean values between the first and follow-up visits divided by the mean SD of the 2 time points) [18] and statistical significance was calculated using the Wilcoxon signed rank test. The Pearson  $\chi^2$  was used to determine the correlation between cognitive flexibility and course of urticaria.

## Results

### Patients

Of the 112 patients suffering from chronic urticaria, 95 were included in the study and completed the PRISM task. Seventeen patients could not be enrolled: 8 refused to participate, 8 could not understand the questionnaire due to linguistic difficulties, and 1 was younger than 12 years of age. The mean age of the 95 enrolled patients was 39.3 (13.6) years (range, 16 to 79 years) and 55 (58%) were women. Median (interquartile range) duration of chronic urticaria at the first visit was 25.6 (13.9-116.3; range, 3-821) months. During the first visit, 64 patients completed the DLQI and Skindex-29 questionnaires. At the follow-up visit, 88 patients completed the PRISM and 57 completed the DLQI and Skindex-29. Seven patients did not complete the follow-up PRISM and 7 patients did not complete the follow-up DLQI or Skindex-29 (Figure 2).

### High Burden of Suffering in Chronic Urticaria Patients

The SIS was high in the 64 patients who completed PRISM, DLQI, and Skindex-29 at their first visit (110.7 [75.2] mm; maximum score, 40.6 [27.5%]). Mean DLQI in the same

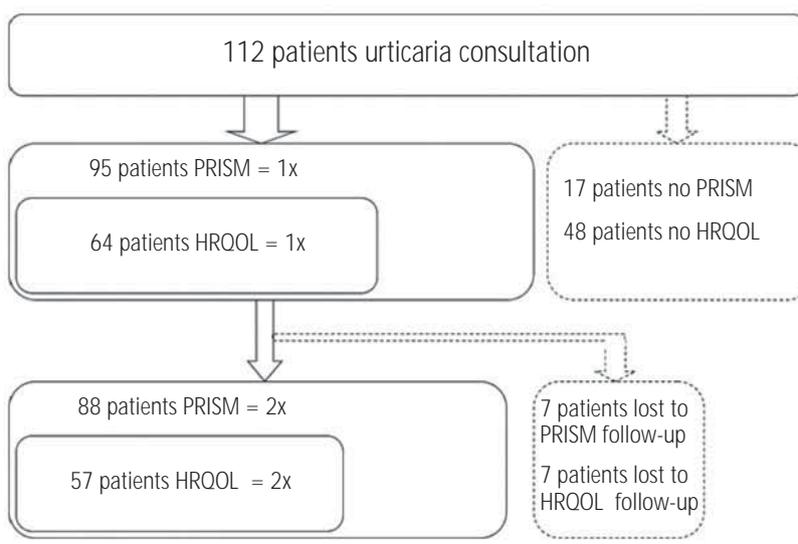


Figure 2. Flowchart of patients. Of the 112 urticaria patients attended at the specialty clinic, 95 were enrolled for PRISM. At the first visit, 64 patients had completed both HRQOL questionnaires. PRISM was completed at follow-up by 88 patients; PRISM and HRQOL were completed at the follow-up visit by 57 patients. 1x: on first visit, 2x: on first and on follow-up visit. HRQOL indicates health-related quality of life; PRISM, Pictorial Representation of Illness and Self Measure.

Table. Change in Suffering Between the First and Follow-up Visit<sup>a</sup>

| n=57                          | Mean 0 | Mean 1 | SD0   | SD1   | Effect Size, d | P Value |
|-------------------------------|--------|--------|-------|-------|----------------|---------|
| PRISM, mm                     | 41.11  | 48.72  | 32.07 | 35.65 | 0.22443557     | .085    |
| Skindex-29                    | 32.74  | 23.58  | 20.38 | 20.23 | 0.45111734     | <.001   |
| DLQI                          | 32.03  | 18.93  | 21.27 | 20.9  | 0.62127085     | <.001   |
| Skindex-29 symptoms           | 37.36  | 27.48  | 18.64 | 20    | 0.5110707      | <.001   |
| Skindex-29 emotions           | 36.52  | 28.09  | 21.67 | 23.52 | 0.37277914     | <.001   |
| Skindex-29 social functioning | 23.46  | 17.55  | 21.45 | 20.58 | 0.28116747     | < 0.001 |

Abbreviations: DLQI, Dermatology Life Quality Index; PRISM, Pictorial Representation of Illness and Self Measure.

<sup>a</sup>Difference in the mean values between first (M0) and follow-up visit (M1) divided by the mean SD of the 2 time points. Expressed by the Cohen effect size (d) and level of significance (P) (Wilcoxon signed rank test)

patients was 10.2 (6.2) (maximum score, 34.0 [20.7%]); mean Skindex-29 was 38.1 (21.6) (maximum score, 32.8% [18.6%]) (data not shown).

PRISM correlated moderately with DLQI and Skindex-29 (Spearman rank correlation coefficient  $\rho = -0.46$  [ $P < .001$ ] and  $\rho = -0.43$  [ $P < .001$ ], respectively).

#### *DLQI and Skindex-29 Indicate an Improvement in Health-Related Quality of Life Over Time, but No Improvement in PRISM*

In the 57 patients who completed PRISM, DLQI, and Skindex-29 at both time points, DLQI and Skindex-29 showed an improvement in quality of life over time. DLQI

was 9.6 (6.4) (maximum score, 32.0 [21.3%]) at the first visit and 5.7 (6.3) (maximum score, 18.9 [20.9%]) at the follow-up visit (Cohen effect size,  $d = 0.62$ ;  $P < .001$ ). Skindex-29 was 37.9 (23.7) (maximum score, 32.7% [20.4%]) at the first visit and 27.4 (23.4) (23.6 [20.2%] maximum score) at the follow-up visit (Cohen effect size,  $d = 0.45$ ;  $P < .001$ ). In contrast to the 2 health-related quality of life questionnaires, PRISM remained unchanged over time: SIS was 112.2 (87.6) mm (maximum score, 41.1 [32.1%]) at the first visit and 133.0 (97.5) mm (maximum score, 48.7 [35.7%]) at the last visit (Cohen effect size,  $d = 0.22$ ;  $P = .085$ ) (Table and Figure 3). Skindex-29 subscores for the 3 areas symptoms, emotions, and social functioning were similar to the composite Skindex-29 scores (Table).

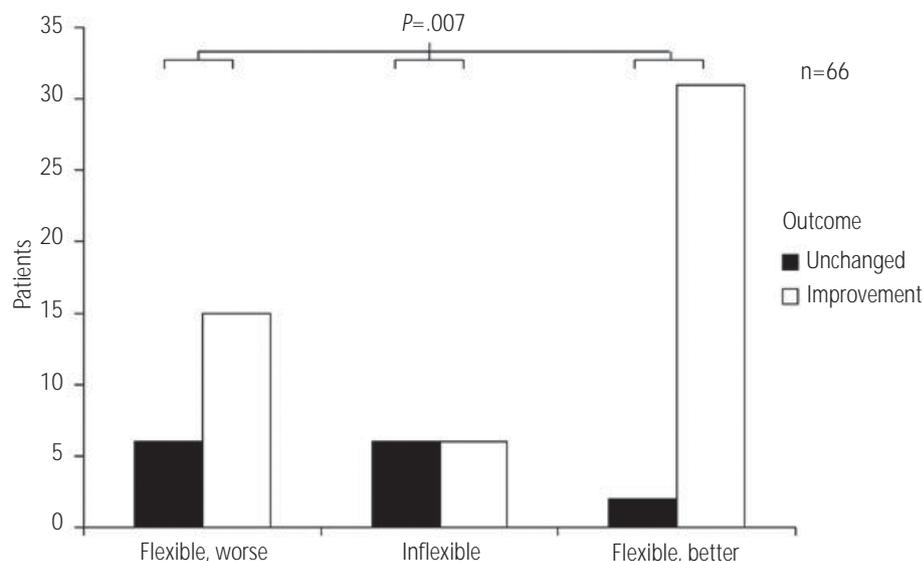


Figure 3. Cognitive flexibility correlates with better outcome in chronic urticaria. Inflexible, Patients assessed as cognitively inflexible by PRISM at the first visit. Flexible, better, Patients with improvement in burden of suffering between the first visit and 2 weeks before. Flexible, worse, patients with deterioration of suffering at the first visit compared to 2 weeks before ( $P = .007$ , Pearson  $\chi^2$ ). Outcome relates to days with urticaria symptoms reported by patients at the follow-up visit. Improvement, Reduction in the number of days with urticaria symptoms by at least 25% within the last month before the follow-up visit. Unchanged, Improvement less than 25% or deterioration of urticaria. PRISM indicates Pictorial Representation of Illness and Self Measure.

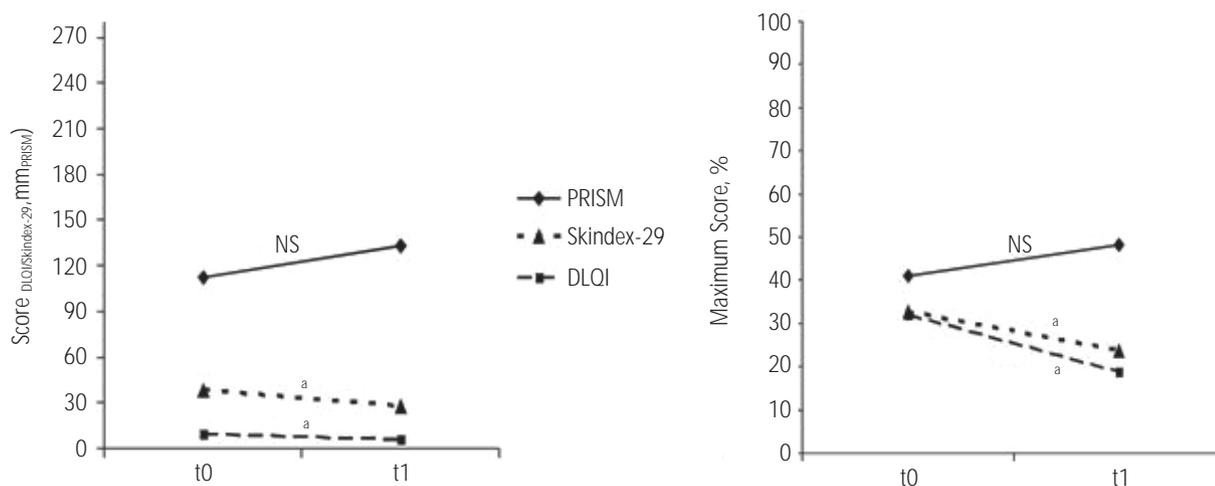


Figure 4. From the baseline visit to the follow-up visit, the Skindex-29 and DLQI scores indicate an improvement in quality of life, whereas the PRISM score remains unchanged. Left, absolute mean scores for PRISM (mm), DLQI, and Skindex-29. Right, Percent mean values of respective maximum scores. <sup>a</sup> $P < .001$  (Wilcoxon signed rank test).  $N = 57$  patients. In PRISM, high scores represent little suffering, whereas in Skindex-29 and DLQI high scores represent considerable impairment in quality of life. DLQI indicates Dermatology Life Quality Index; NS, nonsignificant; PRISM, Pictorial Representation of Illness and Self Measure.

### Cognitive Flexibility Correlates With Better Outcome of Chronic Urticaria

In a subset of 66 patients who were assessed for cognitive flexibility at the first visit using PRISM and who had a complete clinical follow-up, 12 were inflexible, 21 flexible, worse, and 33 flexible, better. Disease course was favorable significantly more often in cognitively flexible patients than in cognitively inflexible patients ( $P = .007$ , Pearson chi-square test) (Figure 4). This was not only true for patients reporting improvement in burden of suffering between the first visit and the previous 2 weeks (*flexible, better*), but also for those reporting increased burden of suffering (*flexible, worse*).

### Case Descriptions

**Patient 1 (Fears):** A 45-year-old man had a 2-year history of chronic idiopathic urticaria with angioedema. The wheals appeared daily. All diagnostic tests were negative and no specific etiology could be identified. In the PRISM task—administered at the first visit—the patient placed the urticaria disk directly on top of the self disk (SIS, 0 mm). DLQI and Skindex-29 showed high scores (17 and 85, respectively). Symptomatic therapy with antihistamines was started. At his next visit 2 months later the patient reported that all wheals had completely disappeared. DLQI and Skindex-29 scores showed a clear reduction (5 and 43, respectively). Surprisingly, once again, he placed the illness disk directly on top of the self disk (SIS, 0 mm). When asked why he still felt such a considerable burden of suffering, he answered that he was afraid of developing angioedema again and suffocating.

This case illustrates that PRISM may help clinicians to better understand a patient's perception of disease, as well as

the implications and assumed complications of the disease. The clinician was able to reassure the patient by explaining to him the mechanisms of the disease and by pointing out that, unlike other forms of angioedema (eg, C1 inhibitor deficiency), angioedema associated with chronic urticaria is extremely unlikely to cause asphyxiation. He provided the patient with a set of tablets for emergency situations. At the last visit, we not only observed a stable reduction in his DLQI and Skindex-29, but also a clear improvement in the PRISM score SIS (145 mm). This case demonstrates how PRISM can reveal and make it possible to address factors that negatively affect a patient's burden of suffering and that could be missed by administering the health-related quality of life questionnaires alone.

**Patient 2 (Close medical attendance):** A 58-year-old woman with a 2-year history of urticaria vasculitis with angioedema presented with daily wheals and unbearable pruritus. Therapy with antihistamines and prednisone were ineffective. In the PRISM task, she placed the illness disk in the middle of the white board (SIS, 130 mm). When asked why the urticaria disk was at such a distance from her despite her severe daily symptoms, she answered that the mere fact of being admitted to an urticaria specialty clinic had diminished her suffering. Therapy was started with dapson and, at her follow-up visit 4 months later, she reported feeling much better, as almost no wheals and only minimal pruritus had occurred. During the PRISM task, she placed the disk outside the board (SIS, 273 mm). In this case, the patient was able to express her feelings nonverbally by PRISM, which helped the clinician to understand that close and intensive medical attendance alone could reduce the burden of suffering. Regular visits to an urticaria specialty clinic may better meet these patients' needs.

In this case, the DLQI and Skindex-29 showed relatively good scores at the first visit and an improvement over time; however, as these instruments do not provide an opportunity for the patient to freely express his/her feelings, they were not able to identify her need for close medical attendance.

## Discussion

The aim of this study was to assess the burden of suffering and impairment of quality of life in patients with chronic urticaria and to compare PRISM with 2 self-administered quality of life questionnaires, DLQI and Skindex-29. PRISM has been validated in a variety of dermatological and nondermatological diseases to measure burden of suffering [7,8]. Given that the clinician's view of impairment and the patient's perception do not necessarily correlate [14], burden of suffering is an important indicator in the management of the disease [19]. In our study, 95 patients with chronic urticaria were monitored over a period of 4 months. Patient characteristics were similar to those reported in other studies on chronic urticaria, with 55 (58%) women and a mean age of 39.3 (13.6) years [20]. We found that most patients (94.7%) had spontaneously occurring urticaria and that only 5 patients (5.3%) were suffering from physical urticaria. Since there may be differences in the burden of suffering between the various types of physical urticaria and spontaneously occurring urticaria (autoimmune, idiopathic), larger-scale studies should be performed to assess these forms separately.

### *High Burden of Suffering and Quality of Life Impairment in Chronic Urticaria*

Several studies have found that patients with chronic urticaria experience impaired quality of life [19,21-25]. Although rarely life-threatening, chronic urticaria in adult patients has been shown to have an impact on quality of life comparable to that of patients with severe coronary artery disease awaiting bypass surgery [22]. Poon et al [23] found that the impaired quality of life in chronic urticaria patients was similar to that of acne patients and higher than in patients suffering from vitiligo, both of which skin diseases are known to significantly affect quality of life. Consistent with these observations, we found highly impaired quality of life in our urticaria patients using DLQI and Skindex-29. PRISM revealed a very high burden of suffering in our patients, as it has already done in patients with other chronic diseases, such as rheumatoid arthritis, chronic obstructive pulmonary disease, and systemic lupus erythematosus [14].

### *Moderate Correlation Between PRISM, DLQI, and Skindex-29*

The correlation between PRISM, DLQI, and Skindex-29 was moderate ( $r=-0.43$ ,  $-0.47$ , respectively), whereas DLQI and Skindex-29 correlate much better ( $r=0.77$ ) (data not shown). We had expected correlations between PRISM and the quality of life questionnaires to be moderate or poor, as PRISM is not primarily intended to measure quality of life,

but burden of suffering, which partly overlaps with quality of life, even though it is not exactly the same.

### *Quality of Life Measures Improve Under Treatment, Burden of Suffering Does Not*

In our cohort, DLQI and Skindex-29 showed a significant improvement in quality of life between the first visit and the follow-up visit. However, the PRISM score remained unchanged. This was a surprising finding and there may be several explanations for it. First, PRISM assesses burden of suffering, whereas DLQI and Skindex-29 measure quality of life. Burden of suffering reflects a person's perception of the intrusiveness and controllability of his/her illness [26] and includes those fears that exacerbate burden of suffering. DLQI and Skindex-29, however, are designed to measure and compare disability in different skin diseases and measure other psychological aspects. DLQI and Skindex-29 measure disability in the preceding week only and thus provide a true picture only in those patients who had active disease. Neither of the 2 questionnaires is disease-specific and may assess some dimensions of quality of life that have little relevance for patients with chronic urticaria, eg, how time-consuming therapy is or the fear of getting scars. Second, PRISM considers the chronicity of urticaria, which often has a relapsing and unpredictable course. PRISM provides a comprehensive measure of burden of suffering and may yield additional and, possibly, more suitable information on a patient's psychological situation than quality of life questionnaires alone.

### *Cognitive Flexibility Correlates With Better Outcome in Chronic Urticaria*

Our study showed a positive correlation between cognitive flexibility, as assessed by PRISM at the baseline visit, and better outcome in chronic urticaria. Interestingly, both patients reporting improvement in urticaria for the 2 weeks preceding the baseline visit (*flexible, better*) and those patients reporting deterioration of urticaria at the baseline visit (*flexible, worse*) had a significantly better outcome than cognitively inflexible patients. The literature does not provide sufficient evidence that cognitive flexibility or a specific state of mind could directly affect the clinical outcome of urticaria. However, it is conceivable that cognitive flexibility affects behavior and adherence to treatment, including taking medication resulting in a distinct clinical outcome. We conclude that cognitive flexibility as assessed by PRISM could be a predictor of a positive outcome in chronic urticaria. If this finding can be reproduced in larger studies, we recommend that PRISM be used to identify patients prone to developing refractory disease and to assign them to a more intensive and comprehensive treatment regimen.

PRISM has several advantages. It requires only simple instructions and little time to complete (2-3 minutes in our patients). We found that patients liked to perform this task and that it facilitated the approach to uncommunicative patients. Rumpf et al [27] recently reported a self-administered version of PRISM. However, it is exactly the direct interaction between patient and clinician that makes PRISM a unique instrument for improved understanding and therapy planning. Our 2

case reports illustrate that PRISM facilitates patient–clinician communication and may have a positive effect on therapy and outcome. The importance of the quality of interaction and communication with patients was recently proven in an online study by Maurer et al [28], who reported that patients suffering from chronic urticaria whose clinicians had also discussed emotional aspects of their disease with them were significantly more satisfied with treatment and more trusting in their physician.

## Acknowledgments

We wish to thank the nursing and laboratory staff from the allergy unit for their assistance with this project. Special mention goes to Dr. med. Thomas Harr, who provided invaluable clinical assistance. We also thank Christian Schindler, PhD (Institute for Social and Preventive Medicine, University of Basel) and Pal Johansen for statistical advice. We are grateful to Priska Rufli for general assistance.

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■ *Manuscript received May 10, 2010; accepted for publication July 21, 2010.*

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