

# Do traditional beliefs about urticaria affect patient satisfaction in South India? – A knowledge, attitude and practices survey

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## Abstract

**Introduction** Chronic urticaria is a distressing condition with a prevalence of 0.5-1% in the population. The factors affecting treatment and physician satisfaction and quality of life are not studied well in Indian patients, in whom traditional beliefs abound.

**Materials and Methods** A cross sectional survey was administered to consecutive patients of chronic urticaria over a six-month period. The survey included questions on previous treatment, their beliefs about the disease, treatment satisfaction (Likert scale), satisfaction with physician and the Dermatological life quality index (DLQI). Logistic regression was done to analyse the independent predictors of treatment satisfaction.

**Results** We included 52 patients with chronic urticaria in our study. In 47 patients, the disease affected their daily life. Fifteen patients believed that their urticaria was related to the lunar cycle. 47 patients were satisfied with daily antihistamines. Age, education, belief about the moon, discussion about diagnosis and treatment were not found to be predictors of treatment satisfaction.

**Conclusion** Strong beliefs about the cause of urticaria, probably region-specific, exist in Indian patients of chronic urticaria. Despite these beliefs, patients are satisfied with intake of daily antihistamines for their urticaria, especially if they are educated about the nature of the disease and the necessity and safety of daily medicines.

## Key words

Urticaria, quality of life, treatment satisfaction, tropical dermatology, attitude.

## Introduction

Urticaria is a common disease which is characterized by itchy short-lived swellings of skin & mucosa due to plasma leakage. Urticaria of at least 6 weeks duration is considered as chronic urticaria (CU).<sup>1</sup> Although second-generation H1 antihistamines are recommended

as first-line symptomatic treatment<sup>2,3</sup>, not all patients respond, and less than half report sufficient symptom control when using these medications as recommended.<sup>4</sup> For non-responders, the guidelines recommend increasing the dosage, adding cyclosporin A or switching to ketotifen; all other options lack adequate scientific evidence.<sup>5</sup>

CU patients reportedly suffer considerable loss of energy, sleep disturbance and emotional upset as well as restrictions in the areas of mobility, home management and work.<sup>6</sup> However, the aspects of quality of life affected by CU remain

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to be characterized in detail.

Maurer et al.<sup>7</sup> studied the doctor-patient relationship in 321 patients of chronic urticaria in Germany in an internet survey. Only two in three respondents were taking prescription medication. The scale of this problem in the Indian scenario has not been studied. We expect it to be different here because patients are far more tuned to native medicine and traditional beliefs and are less likely to accept allopathy-based treatment for this chronic problem.

There is no data in India on patient's beliefs and how it affects perception of their doctors sometimes "contrary to belief" explanation and the treatment offered. Hence this knowledge, attitude and practice survey was undertaken.

### Materials and methods

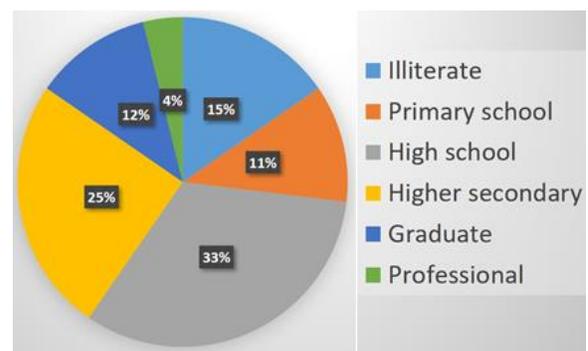
The study was designed as a cross sectional survey done over a period of six months. All consenting patients suffering from chronic urticaria were included in the study. Individuals suffering from psychiatric co-morbidity or other chronic illnesses and children were excluded from the study. After obtaining the approval of the institute ethics committee, all the patients of chronic urticaria satisfying the inclusion criteria, were surveyed using a questionnaire and the data was entered into a proforma. The questionnaire was administered by a dermatologist. The survey included the Dermatology life quality index (DLQI) questionnaire and questions regarding previous treatment taken, both prescription and over-the-counter. Questions regarding treatment preference, expectations, satisfaction with doctor, doctor's explanation of disease, patients' own perception of cause of disease, willingness to accept doctor's explanation, aggravating factors and relieving factors were incorporated into the survey. The urticaria activity score (UAS) was calculated for all the patients. Data

collected was summarized as proportions and means. Logistic regression was done to look at the independent predictors of treatment satisfaction. Microsoft excel and Stata version 12 (Stata Corp LLC, Texas) was used for data analysis.

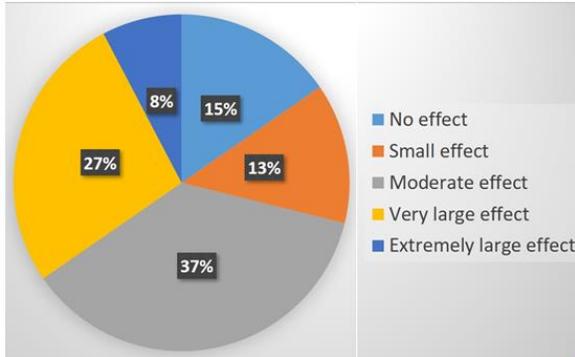
### Results

We included 52 patients of chronic urticaria in our study. The population studied consisted of 39 female patients (75%) and 13 male patients (25%), with a mean age of 35 years (range 12-65). In this sample, 8 (15%) were illiterate and 21(40.38%) had completed higher secondary education and beyond (**Figure 1**). The mean duration of disease at the time of presentation to us was 15 months (range 2 months – 5yrs). None of the participants had family history of chronic urticaria. Dermatology life quality index (DLQI) was 0-1 (no effect on daily life) in 5 patients, 2-5 (small effect on daily life) in 8 patients, 6-10 (moderate effect on daily life) in 21 patients, 11-20 (very large effect on daily life) in 14 patients, and 21-30 (extremely large effect on daily life) in 4 patients (**Figure 2**).

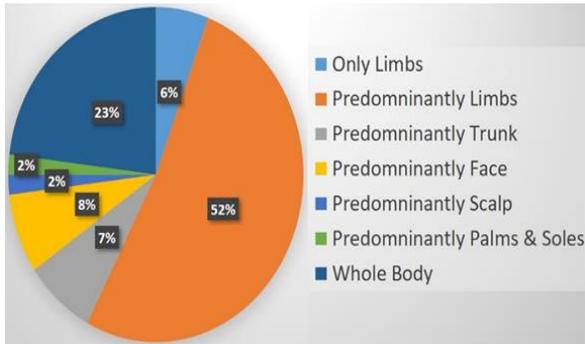
The mean DLQI was 9.71. In forty two (81%) patients, the frequency of wheals was 5 on Likert scale (i.e. one to two episodes daily). In 10 (19%) patients, the number of episodes ranged from 4 to 5 episodes per week (i.e. 4 in Likert scale).



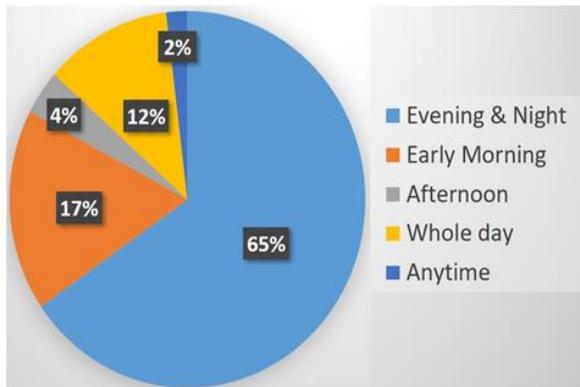
**Figure 1** Educational status of chronic urticaria patients surveyed



**Figure 2** Dermatological life quality index (DLQI) of patients of chronic urticarial



**Figure 3** Site of wheals in patients surveyed



**Figure 4** Time of onset of wheals in patients surveyed

The most common site affected by wheals was found to be the limbs (**Figure 3**). 34 (65%) patients reported getting wheals in the late evening and night between 6 pm to 10 pm (**Figure 4**). Autologous serum skin test (ASST) was done in 42 out of the 52 patients enrolled in our study. Seven patients had dermatographism; so ASST was not done in these patients. Three patients denied consent for ASST. ASST was

found to be positive in 37 (88.09%) patients. Twenty four (42%) patients had associated angioedema, out of which 12 (50%) reported frequency of  $\geq 4$  in Likert scale. Seven patients had dermatographism along with urticaria. Regarding coexistence of other autoimmune diseases, 5 patients had hypothyroidism and two patients had both hypothyroidism and vitiligo. Disease activity was evaluated by the Urticaria Activity Score (0-6). The mean UAS in our study was 4.3 with 56% patients having UAS of  $\geq 5$ .

Ten (19.23%) patients took other forms of treatments i.e. homeopathy, ayurvedic, siddha etc. before consulting a physician or a dermatologist. Of these, 5 patients discontinued treatment in less than one month, either because they did not get relief or recurrence occurred after stopping treatment or due to the development of undesirable side effects. On enquiring patient's belief about the cause of disease, 23 (44.23%) attributed food as the cause, especially foods like brinjal, fish, dried fish, chicken, with 13 (56.52%) patients having strength of belief of 7 and the mean of strength of belief calculated on Likert scale being 6.06. Three patients (5.26%) attributed the cause to insect bite specifically centipede bite, and strength of belief was  $\geq 5$  in 2 patients. Ten (19.23%) patients attributed both food and insect bite as the cause of urticaria with 7 (70%) patients having a strength of belief of 7. One patient thought that his disease was due to dust allergy with strength of belief of 7 on Likert scale. Fifteen (28.84%) patients believed that there was no relation of specific food with their urticaria. Fifteen (28.84%) patients felt that their disease aggravates and remits in relation to the waxing and waning of the moon with 13 (86.66%) patients having a strength of belief of 7; and the mean strength of belief calculated on Likert scale was 6.4. Eight patients reported that there was an aggravation on new moon day and

7 patients reported that there was an aggravation on both full moon and new moon day. Out of 52, 11(21.15%) patients thought that the disease was fatal, one patient complained of suicidal thoughts, 12 (23.08%) patients thought that this disease may lead to other complication; the rest of them did not have any idea about it.

Prior to visiting our outpatient department, twenty seven (51.92%) patients consulted a dermatologist, 11(21.15%) patients consulted both a dermatologist and a general physician. Among these 11 patients, 6 (54.55%) patients reported that they were not satisfied with both as disease was not cured. Three (27.27%) patients told that they were more satisfied with the general physician, possibly due to injectable long acting corticosteroid. Only 2 patients had been explained about the disease course and treatment and both of them had consulted a dermatologist. On enquiring about quality of care provided by their treating physician, 43 (82.69%) patients told its  $\leq 2$ . The mean 'quality of care' calculated by Likert scale was 1.98. Eight (15.38%) patients were given only oral tablets and 34 (65.38%) patients received both oral and injectable medications. On enquiring about route which satisfied them the most, 35 (67.30%) patients were most satisfied with oral tablets. On enquiring about drug preference, 50 (96.15%) patient told that they prefer long term symptomatic treatment with drugs with better safety profile, than drugs which offer chance of cure or longer remission with adverse safety profile.

After having been explained about the disease course, its nature and treatment modalities, 47 (90.38%) patients told that they are satisfied with daily antihistamines, with 43 (91.48%) patients having a satisfaction level  $\geq 3$ ; the mean of 'level of satisfaction' calculated by Likert scale was 3.5. The cause of dissatisfaction or less satisfaction in some patients was the

daily intake of tablets and the inability of the drug to cure the disease. It was explained to the patients that chronic urticaria requires daily tablets like diabetes or hypertension; but the disease and the medication does not have any systemic complications or long term adverse effects, which was the main worry of the patients. After proper explanation about the disease, 33 patients (63.46%) reported that they received emotional support from their physician, while 7 patients reported that did not receive emotional support and 12 could not comment. Only 9 (17.31%) patients out of the total 52 needed more than 10mg of cetirizine per day for maintenance of remission. In the rest of the patients, remission was maintained with 10mg of cetirizine daily. Logistic regression was done to see if age, education, sex, beliefs about relation to moon, the doctor discussing about diagnosis and treatment were independent predictors of satisfaction with doctor. However, none of these variables were found to be independent predictors of treatment satisfaction.

## **Discussion**

The prevalence of urticaria is between 0.5% and 1%, with a higher prevalence in women.<sup>8</sup> Chronic spontaneous urticaria has a negative impact on patients' quality of life, reduced work performance and direct and indirect healthcare costs.<sup>9</sup> Consistent with previous reports, this survey also found that chronic urticaria has profound impact on quality of life. Forty seven out of 52 subjects had scores affecting their DLQI, with large and very large effect on daily life in 18 patients.

In some Tamil patients of urticaria, there are certain strong beliefs about the cause of chronic urticaria, which persist despite the treating physicians counselling and reassurances to the contrary. 44% of patients believed that their disease was related to food especially brinjal and

non-vegetarian food. 28% patients believed that the severity of their symptoms was related to the lunar cycle. 5% patients thought that their disease was due to the bite of a centipede. This was despite the fact that 40% of patients were educated till higher secondary school and beyond. These beliefs are quite strong and may affect the patient's adherence to antihistamines. Dermatologists need to be aware of this and take extra efforts to counsel patients in order to ensure patient compliance. Other parts of India might have similar beliefs, which are unique to those subsets of patients of chronic urticaria.

In comparison with general practitioners, dermatologists are more likely to explain about the nature of the disease and its course. Two patients were thus explained about the disease and they were satisfied with the treating doctor. The other patients were dissatisfied and reported a mean quality of care of 1.98 by Likert scale. As urticaria is a disease with no permanent cure, talking to the patient and lending emotional support makes a significant difference in the satisfaction of patients. This has been reported by Maurer et al, who found that patients whose physicians had discussed the emotional aspects of urticaria with them were significantly more satisfied with the treatment and more trusting of their physicians.

Sixty seven percent patients reported that they were more satisfied with oral tablets when offered both oral tablets and injectable medications as treatment options. Commonly, patients with urticaria are prescribed injectable anti histamines or injectable long acting steroids by many general physicians and dermatologists, in a bid to provide fast relief from symptoms and provide longer remissions. Sixty five percent of our survey patients had also received both oral and injectable medications in the past. Despite the possibility of fast relief and longer remission, more patients were satisfied with oral

tablets. This knowledge makes it easier for dermatologists to be compliant with the guidelines advocating non sedating antihistamines as first line treatment of chronic urticaria, thereby reducing the unnecessary steroid injections. Also, 96% patients reported that they preferred long term safe drugs offering symptomatic treatment over drugs with adverse safety profile, even if they offered promise of longer remission or cure. Antihistamines are drugs with good safety profile and can be preferred over steroids and immunosuppressants, in view of this response by the majority of patients. After being explained about the nature of disease, 90% of patients were satisfied with the use of long term antihistamines. This implies that with proper counselling and explanation, it is very easy for dermatologists to follow the first line treatment for urticaria, according to guidelines. No independent predictors of treatment satisfaction were found in our study, probably because of the small sample size. Among 52 patients, only 9 patients required up dosing of cetirizine, thus highlighting the efficacy of non sedating antihistamines in the management of this distressing condition.

In conclusion, our study shows that despite the prevalence of strong, probably region- specific beliefs about its cause, patients are satisfied with long term antihistamines, provided that the patients are educated sufficiently about the disease. Our study is limited by the small sample size, lack of follow up and lack of an urticaria specific quality of life questionnaire. Further studies with larger sample size may be required to corroborate our findings.

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