

Original article

Chronic urticaria: a patient survey on quality-of-life, treatment usage and doctor–patient relation

Background: Chronic urticaria (CU) is a common skin disorder characterized by recurrent spontaneous outbreaks of itchy wheals and/or angioedema. It has been shown to have substantial impact on patient quality-of-life, but little else is known about patient perspectives on CU and its treatment.

Methods: An internet survey was conducted with 321 randomly selected, representative adults in Germany and France who were diagnosed with CU. The survey included the Skindex-29 questionnaire on quality-of-life and questions about treatment usage and patients' relation to their physician. Regression analyses were used to identify predictors of quality-of-life, use of prescription medication and various aspects of the doctor–patient relation.

Results: The survey confirmed that CU has substantial impact on quality-of-life, with median Skindex scores of 68 for symptoms, 50 for functioning and 53 for emotions. Only two in three respondents were taking prescription medication for their CU. Older respondents, French respondents and fully employed respondents were significantly ($P < 0.01$) more likely to be taking prescription medication. Only three in five respondents under a physician's care reported that their physician had discussed the emotional impact of CU on them. Patients whose physicians had discussed this emotional impact were significantly ($P < 0.001$) more satisfied with treatment and more trusting of their physician.

Conclusions: CU has a heavy impact on quality-of-life. Physicians need to be aware that many patients are not taking second generation anti-histamines and counsel them better on this point. Physicians should also discuss the emotional impact of CU with patients, because it improves their satisfaction and trust.

**M. Maurer¹, J.-P. Ortonne²,
T. Zuberbier¹**

¹Department of Dermatology and Allergy, Allergie-Centrum-Charité, Charité – Universitätsmedizin, Berlin, Germany; ²Department of Dermatology, Hôpital de L'Archet 2, Nice, France

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M. Maurer
Department of Dermatology and Allergy
Charité – Universitätsmedizin
Charitéplatz 1
D-10117 Berlin
Germany

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Chronic urticaria (CU) is a common skin disorder, characterized by spontaneously arising itchy wheals and/or angioedema present on a regular basis for longer than 6 weeks (1–5). In the majority of cases, the cause remains unknown (4, 5). Although second-generation H₁ antihistamines are recommended as first-line symptomatic treatment (1–3, 6), not all patients respond, and less than half report sufficient symptom control when using these medications as recommended (4, 5). For non-responders, the guidelines (6) recommend increasing the dosage (up to 4×), adding cyclosporin A or switching to ketotifen; all other options lack adequate scientific evidence (6). Consequently, many CU patients remain afflicted by the condition, which has repeatedly been found to have a substantial impact on patient quality-of-life (QoL) (7–9).

Even though CU often lasts for many years and substantially impacts sufferers' lives, treatment is always provided on an outpatient basis and left largely at the

discretion of the patients, who may only visit their physicians sporadically. Thus a physician may only have intermittent opportunities to try to help CU patients. It is therefore important for physicians to have a better understanding of who their CU patients really are, what their orientation towards treatment is and what they are expecting from their physician as part of good health care. Unfortunately, little is known about CU patients themselves, whether they follow recommended treatment, or how they view their relationship with their physician.

Because CU is a long-term condition that is challenging to manage and has a significant impact on patient QoL, we were interested to know how the patients themselves view their condition, the available treatment and their physicians' care. An internet survey was conducted in France and Germany with subjects who reported having been diagnosed with CU by a medical professional. The aim of the present analysis was to get a deeper understanding of the impact of CU on respondents'

QoL, their usage of treatment and their relation with their physician. We were especially interested to know which patients do not use prescription medication and whether discussing the emotional impact of CU benefits the doctor–patient relation.

Methods

Survey

The survey was written in English and translated into French and German by a native speaker of each target language living in the respective country. The translations were checked for equivalence to the English by separate native-speaking translators of the target language in each of the countries. The translated survey was piloted as a paper version administered in-person with three respondents in each country, and a brief interview was conducted afterwards to check for difficulties in the survey. The full survey was conducted via the internet (10) in France and Germany, from mid-October to mid-November, 2006.

The survey began with a brief screening section covering some sociodemographics and verifying the respondent's urticaria. The main part of the survey contained roughly 110 questions, depending on the respondent's answers, mostly involving Likert-scale ratings, quantitative questions, yes/no lists and multiple choice questions. The content items of the survey covered topics such as: the patients' general health attitudes; CU duration, frequency and timing; how the initial diagnosis occurred; previous and present treatments; the role of their treating physician and sociodemographics. Skindex-29, a validated questionnaire on the quality-of-life (QoL) of dermatology patients, (11–13) was embedded into the survey. In the present paper we focus selectively on the subset of data related to patient QoL, treatment usage and relation to their physician.

Subjects

Survey respondents were drawn from an established pool of survey 'panelists' in France and Germany. 'Panelists' were initially recruited either by telephone from random dialing lists or online from a variety of website ads, and they were invited to join the panel to participate in online surveys. Panelist behaviour is monitored by quality assurance teams who deregister panelists whose responses are of questionable validity. The sample for this particular survey was pulled in two phases. In the first phase, panelists preidentified as hives sufferers, ages 18–65, were invited within each country; in the second phase, invitation was sent to any panelist age 18–65 (with screening for urticaria only in the survey itself). In both phases, panelists were randomly selected for invitation.

The survey began with screening questions. The exclusion criteria were: (1) occupation of the respondent or any immediate family member in marketing, market research, advertising, health-care products, pharmaceuticals or health care professions (doctor, nurse or pharmacist); (2) age under 18 or over 99. Maximum quotas were set for age and sex to keep the sample of participants fairly representative of the adult population demographics of the countries, and respondents were excluded when the maximum quotas were filled. The inclusion criteria were: (1) a 'yes' response to the question, 'Have you ever suffered from a spontaneous outbreak of hives that lasts for 6 weeks or longer (also known as chronic hives or chronic urticaria)'; (2) a response of '1' or greater to the question, 'Approximately how many spontaneous outbreaks of hives lasting more than 6 weeks (chronic urticaria) have you experienced within the past 12 months'?

Data analysis

The pool of respondents of the individual countries was weighted (14, 15) by sex and age to reflect the demographics of each country, based on national census data. After applying the exclusion criteria, this weighting was applied to all respondents, so that the initial pool of respondents was representative by sex and age for the total adult population of the respective countries. The regional distribution of respondents was also compared to census data. It was found to be adequately representative, so no weighting was applied for geographic region. In addition, the data for the total sample was weighted to accurately reflect the relative sizes of the two countries' adult populations. Then after this weighting, the screening questions for the inclusion criteria were applied to this pool of respondents.

Regression analysis was performed to assess the influence of the five sociodemographic variables (sex, age, nationality, education and employment) on various survey responses as dependent variables. Multiple linear regression was used for continuous dependent variables; logistic regression was used for binary dependent variables. The data met all the necessary assumptions for use of these regression models. Statistics were performed with SPSS v.15.0 (SPSS, Chicago, IL, USA). Statistical graphing was with performed with SPSS v. 15.0, Excel 2003 (Microsoft, Seattle, WA, USA), R v. 2.6.2 (R Foundation for Statistical Computing, Vienna, Austria) and Adobe Illustrator 10 (Adobe, San Jose, CA, USA).

Results

Survey population

After applying the exclusion criteria, there were 8036 subjects in the initial pool of respondents (4035 in Germany and 4001 in France). Data weighting for sex and age was applied, so that this initial pool of people questioned would be representative for the respective populations. After applying the inclusion criteria, 405 adults with CU in Germany (208) and France (197) were eligible to complete the main survey, and they all did. During the survey, respondents were asked if they had ever been diagnosed with chronic hives/urticaria by a medical professional. Respondents who replied 'no' were removed from the data analysis of this paper, leaving a total physician-diagnosed survey population of 321 weighted respondents (169 German, 150 French). The basic sociodemographics of the survey participants are presented in Table 1.

There were 268 (83.5%) respondents who were under a physician's care for their CU. They were distributed roughly evenly between dermatologists ($n = 111$, 34.6%), general practitioners ($n = 81$, 25.2%) and allergists ($n = 74$, 23.1%) [other: $n = 3$, 0.9% (2 immunologists, 1 unspecified)]. The remaining 53 (16.5%) respondents reported that they were not under a physician's care for the treatment of their chronic hives, even though they had at one time been diagnosed by a medical professional. Regression analysis was used to better identify who these respondents tend to be sociodemographically. Employment status was the strongest predictor, whereby subjects who were not employed full-time were two and a half times as likely to not be under a physician's care for their CU than respondents who were employed full-time.

Table 1. Sociodemographics of the survey respondents

	Total	France	Germany
<i>Sex</i>			
Female	186 (58.1)	87 (57.6)	99 (58.4)
Male	134 (41.9)	64 (42.4)	70 (41.6)
<i>Age</i>			
25th quartile	29.5	30.0	28.8
Median	37.0	35.0	39.0
75th quartile	47.0	47.0	48.0
<i>Education</i>			
Elementary school or middle school	53 (16.6)	11 (7.4)	39 (22.9)
High school	58 (18.1)	23 (15.0)	34 (20.1)
Vocational/technical school	72 (22.4)	26 (17.6)	43 (25.6)
University	108 (33.7)	67 (44.5)	45 (26.4)
Graduate school	29 (9.2)	23 (15.5)	8 (4.9)
<i>Employment status</i>			
Full-time (≥ 32 h/week)	186 (58.0)	99 (65.9)	89 (52.5)
Part-time (< 32 h/week)	49 (15.3)	15 (9.9)	32 (19.0)
Homemaker/caregiver	22 (6.8)	8 (5.5)	13 (7.7)
Not working/retired	38 (11.7)	18 (12.0)	20 (11.6)
Full-time student	18 (5.7)	6 (4.2)	11 (6.7)
Unemployed, looking for work	8 (2.5)	4 (2.5)	4 (2.4)

Data is presented as $n(\%)$, except age presented in years. Slight numerical discrepancies here and elsewhere in the report are due to rounding off of fractions in the data weighting.

(OR = 2.64, $P = 0.004$). There was a tendency for women (OR = 1.88, $P = 0.051$) and older respondents (OR = 1.02 per year of age, $P = 0.095$) to not be under a physician's care for their CU. We also compared the Skindex scores (see below) and the trust score (see below) of the 53 subjects not seeing a physician to the 268 subjects who were seeing a doctor. Although the means for all three Skindex subscale scores and the trust score were statistically significantly lower in the 53 subjects not seeing a physician (not shown), the absolute difference in the means was not large and the scores were not nearly low enough to serve as a clear and sufficient explanation for why these subjects were not under a physician's treatment for their CU.

Quality-of-life

Skindex was used to assess the respondents' quality-of-life. The regression analysis identified sex as the only significant predictor of the Skindex symptoms score ($P < 0.001$), whereby women were more affected than men. None of the sociodemographic variables significantly predicted the Skindex functioning or emotions scores. The Skindex scores are presented in Fig. 1. As can be seen, CU has a substantial impact on QoL for almost all people.

Treatment usage

The survey included a few questions about attitudes toward the usage of medication. These findings are

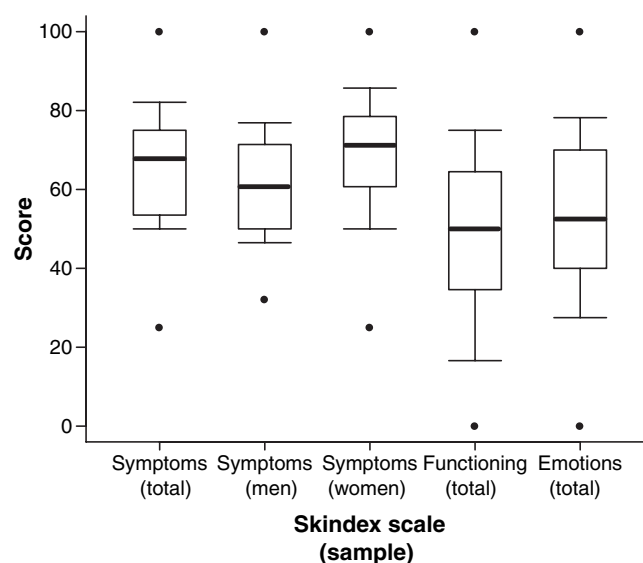


Figure 1. Quality of Life as measured by the Skindex-29 questionnaire. The box-and-whisker plots present the Skindex scores for the symptoms, symptoms of males, symptoms of females, functioning and emotions subscales. The solid line inside the box presents the median. The lower end of the box presents the 25th percentile score; the upper end of the box is the 75th percentile. The lower whisker line presents the 10th percentile score; the upper whisker line is the 90th percentile. The lower dot presents the minimum score; the upper dot is the maximum.

presented in Fig. 2. As can be seen, a high proportion of people with CU are reluctant to take medications in general. The survey asked participants what they typically do when they experience an outbreak. These findings are presented in Fig. 3. As can be seen, only about two-thirds of all survey respondents use prescription medication.

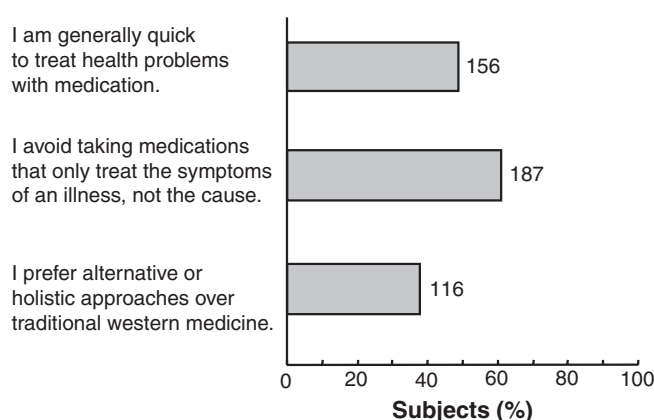


Figure 2. General attitudes toward taking medication. For each of the three statements, there were five possible answers: definitely true, mostly true, do not know/not sure, mostly false, definitely false. The numbers to the right of the bars are the n of respondents who replied 'definitely true' or 'mostly true'; the length of the bars shows the corresponding percent of respondents.

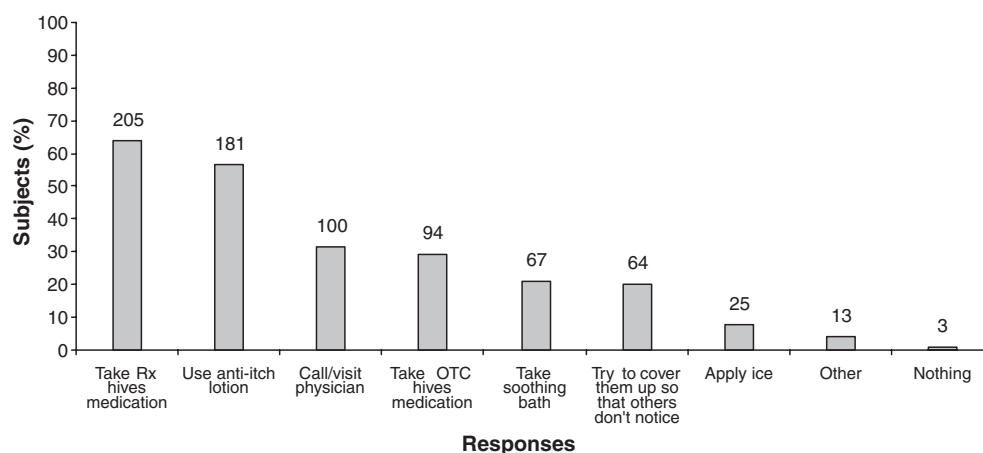


Figure 3. Patient response to a CU outbreak. Respondents were asked, 'What do you typically do when you experience an outbreak?' Multiple replies per respondent were permitted. The numbers on top of the bars are the number of weighted respondents who gave the indicated reply; the height of the bars shows the corresponding percent of respondents.

Regression analysis was used to better identify who takes prescription medication, including the five sociodemographic variables and the type of physician as independent/control variables. Not surprisingly, patients seeing a GP, dermatologist, or allergist were significantly more likely to be taking prescription medication when compared binarily to all others ($P < 0.001$). Younger respondents were less likely to be taking prescription

medication (OR = 0.969 for each decreasing year of age, $P = 0.005$). Respondents who were not employed full-time were half as likely to be taking prescription medication as respondents employed full-time (OR = 0.44, $P = 0.005$). German respondents were half as likely as French respondents to be taking prescription medication (OR = 0.45, $P = 0.007$). The actual rates of usage of prescription medication are presented in Fig. 4.

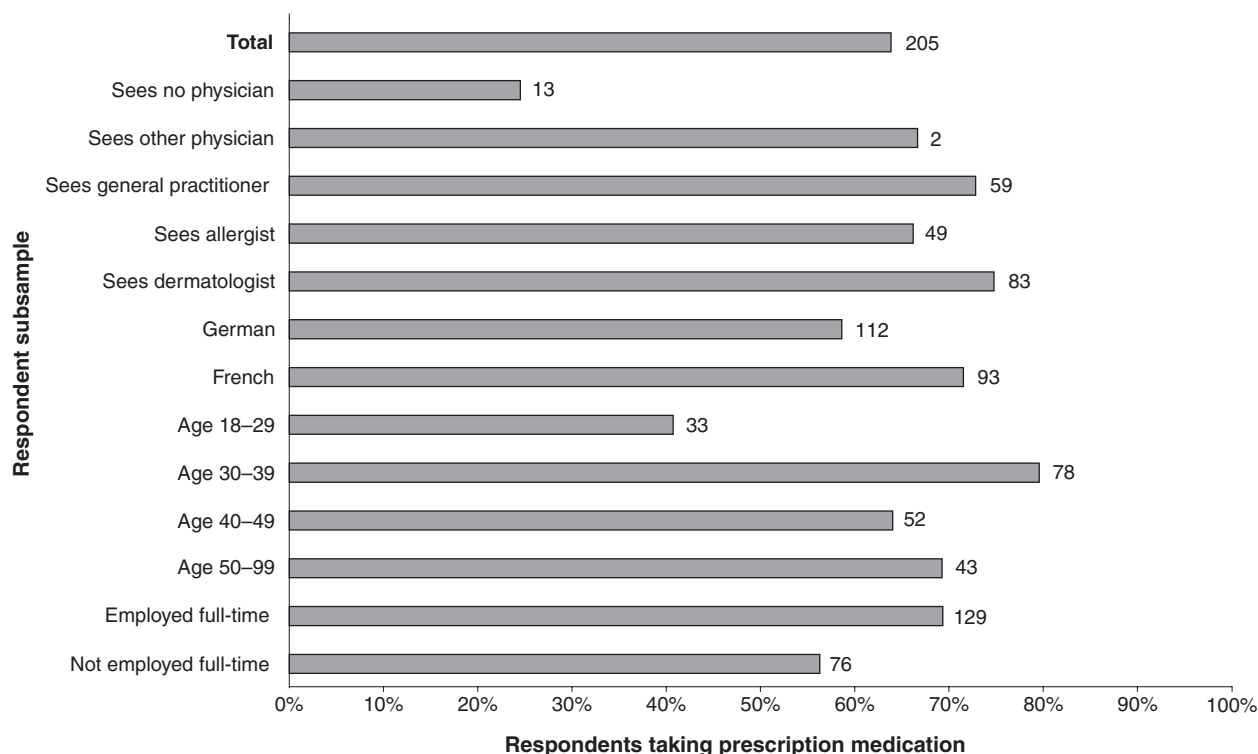


Figure 4. Portion of respondents using prescription medication. Respondents were asked, 'What do you typically do when you experience an outbreak?' One possible response was, 'Take prescription hives medication'. The bars show the percentage of subjects from various subgroups who were taking prescription medication for CU. The numbers at the ends of the bars are the actual number of weighted respondents from that subgroup who were taking prescription medication.

Doctor–patient relation

Regression analysis was used to determine which patients reported that their physician discussed with them the emotional impact on them from CU. Sex was the only sociodemographic variable that significantly predicted the physician discussing emotions ($P < 0.001$), whereby, interestingly, men were more than three times more likely than women (OR = 3.4) to report that their physician discussed the emotional impact of CU with them. Also interestingly, when comparing patients seeing an allergist to patients seeing GPs, allergists were significantly ($P = 0.02$) more likely to discuss the emotional impact of CU, doing so more than twice as often (OR = 2.4) as GPs. The percentages of patients reporting that their physician discussed the emotional impact of CU are presented in Fig. 5.

Regression analysis was used to determine which patients reported higher or lower satisfaction with their physician, according to the five sociodemographic variables, the type of physician and whether or not the physician discussed the emotional impact of CU. If the physician discussed the emotional impact of CU, the respondent was significantly ($P < 0.001$) more likely to be satisfied with the treatment. The only other significant predictor of satisfaction was education ($P = 0.02$), whereby patients with higher levels of education were slightly more satisfied. The satisfaction scores are presented in Fig. 6.

Regression analysis was used to determine which patients reported higher or lower trust in their physician, according to the five sociodemographic variables, the type of physician and whether or not the physician discussed the emotional impact of CU. If the physician discussed the emotional impact of CU, the respondent was

significantly ($P < 0.001$) more likely to report a high level of trust in their physician. The significant socio-demographic predictors of trust were sex ($P = 0.02$) and employment status ($P = 0.03$), whereby women and fully employed respondents were somewhat more likely to report high trust in their physician. Interestingly, when comparing patients seeing an allergist to patients seeing GPs, patients seeing an allergist were significantly less likely to report having high trust in their physician ($P = 0.046$), after controlling for all other variables in the model. The trust scores are presented in Fig. 7.

Discussion

Consistent with past reports, (7–9, 16) this survey confirmed that CU had a substantial impact on these respondents' quality-of-life. As seen in Fig. 1, the median score on each of the three subscales was at least 50 on a 0–100 scale. This would imply that such a respondent is, on average, giving the middle score for every item of how CU impacts on his or her life. It can also be seen that even the lower 25th percentile of respondents is still reporting a substantial impact of CU on QoL; while the upper 75th percentile of respondents is reporting a very substantial impact on QoL. Interestingly, it can be seen that about 10% of CU sufferers (the lower 10th percentile) are able to cope with the condition very well: although their symptom subscale score is still nearly as high as the median's, their emotional and functional subscales are comparatively mild. It would be illuminating to know more about why and how these rare respondents are able to cope with CU so much better than everyone else. At the high end – the upper 90th percentile of respondents – it can be seen that CU can continue to impact even worse

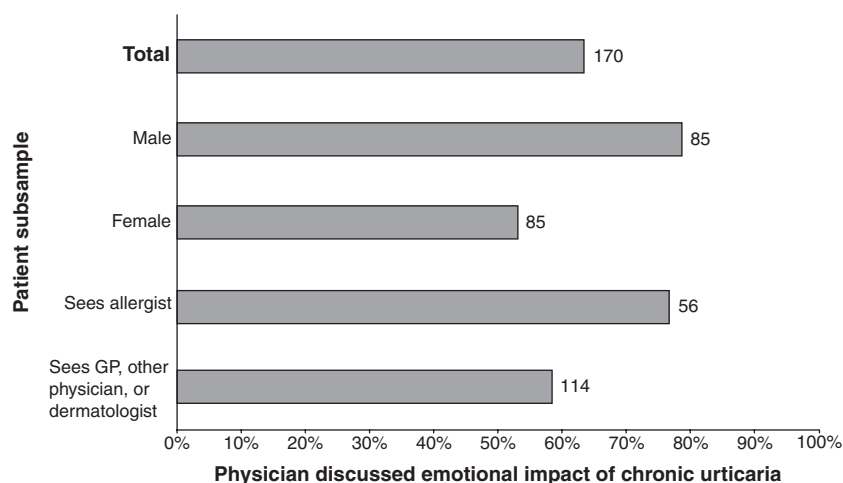


Figure 5. Portion of physicians who have discussed the patient's emotions. Respondents under a physician's care for their chronic urticaria ($n = 268$) were asked, 'Has [your] physician ever discussed with you the emotional impact that chronic hives may have on your life (e.g. anxiety, worrying about your condition)?' The length of the bars shows the percentage of respondents who replied 'yes'; the numbers at the ends of the bars are the actual number of weighted respondents.

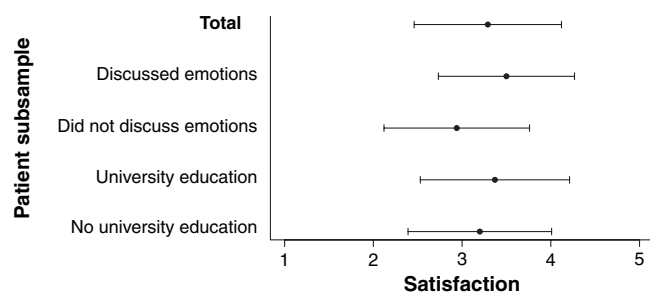


Figure 6. Patient satisfaction with the CU treatment from their current physician. Respondents under a physician's care for their chronic hives ($n = 268$) were asked, 'Overall, how satisfied are you with the treatment you receive from [your] physician?' There were five possible answers (not at all satisfied, not very satisfied, somewhat satisfied, very satisfied, extremely satisfied), which were coded 1–5. The dots in the graph present the mean satisfaction scores, and the whiskers present the standard deviation.

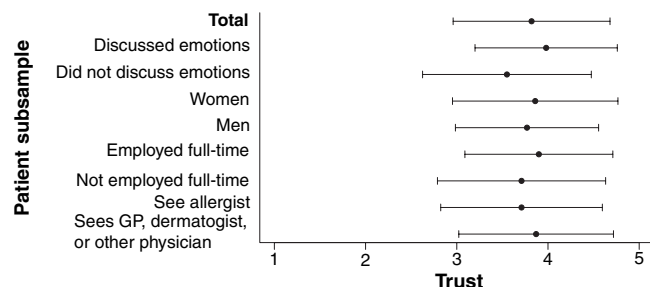


Figure 7. Patient trust in their physician. Respondents were presented with the statement, 'I have a high level of trust in my physician'. There were five possible answers (definitely false, mostly false, do not know/not sure, mostly true, definitely true), which were coded 1–5. Only respondents who were under a physician's care for their chronic hives ($n = 268$) were retained in this analysis. The dots in the graph present the mean trust scores, and the whiskers present the standard deviation.

on a patient's QoL without reaching a ceiling limit. It was also noteworthy that women had worse Skindex symptoms scores than men, which might reflect differing anatomical distribution of symptoms (17) or different underlying pathomechanisms (18). Thus with few exceptions, when CU patients visit their physician, they feel emotionally distressed and are looking for help with more than just their visible skin symptoms – indeed perhaps much more.

In an earlier study (16) we examined the impact of CU on QoL in 100 CU patients with moderate to severe daily symptoms. Surprisingly, we found in that study that 1 in 2 (!) CU patients have psychiatric co-morbidity (mostly anxiety, depression or somatoform disorders). Interestingly, CU patients with psychiatric co-morbidity had significantly poorer QoL and the pooriness of their QoL correlated directly with the severity of their psychiatric

morbidity (16). Similarly, a large study of dermatology outpatients using conservative measures also found a high rate of psychiatric morbidity among urticaria patients (35% – higher than almost any other dermatological diagnosis in their study), and they found a strong correlation between psychiatric morbidity and worse QoL as assessed by Skindex-29 (19). Many other studies have also reported various psychological problems among CU patients (20–23). It is not yet known though whether psychiatric co-morbidity is the result of CU or whether it is a predisposing factor for CU (through psychophysiological mechanisms or poorer treatment choices and noncompliance), or both.

Thus the CU patient arrives to the physician's office not only with a skin problem but also with impaired quality-of-life and often psychiatric symptoms as well (mainly anxiety, depression and somatoform disorders (16)). The most recent treatment guidelines all state that CU should be treated with nonsedating second-generation antihistamines (1–3). The guidelines assume that all patients will always follow their doctor's advice and take the recommended treatment, but unfortunately our survey found this not to be the case. Physicians need to remain aware that patients may not be following treatment, especially if there is little initial success. Only about half the patients are generally eager to treat health problems with medication (Fig. 2) and only about two in three patients actually use prescription medication (Figs 3 and 4). People suffering from CU but not seeing a doctor for treatment account for one-third of these respondents not taking prescription medication, so drawing them back into the medical health care system would improve this shortfall. It is important to note that people who were not employed full-time were much less likely to be under a physician's care for the treatment of their CU; this is an important issue for policy makers to address. German patients, young patients and patients not working full-time were also less likely to be taking prescription medication, so physicians treating these patients may need to make extra efforts in educating them about treatment.

Yet physicians should not focus narrowly only on a patient's CU and drug treatment, as unfortunately appears to sometimes be the case. Two in five patients reported that their doctor had never discussed their emotional well-being with them (Fig. 5). As shown in Fig. 1 and as reported in several past studies (7–9), CU (or the psychiatric co-morbidity wrapped up with it (16)) has a substantial impact on patients' emotional well-being, their quality-of-life and thus ultimately their overall healthiness. By not discussing a patient's emotions, the physician misses the opportunity to identify and address possible hidden psychiatric problems and to help the patient manage the impact of CU on their daily life. By contrast, discussing the emotional impact of CU increases a patient's satisfaction with treatment (Fig. 6) and trust in their physician (Fig. 7). A previous study has

shown that physicians' interpersonal skills are the most relevant factor for determining the satisfaction of dermatology outpatients (24). They suggested that improving interpersonal skills might improve patient satisfaction and thus compliance with treatment.

Due to the cross-sectional design of this survey, we cannot determine whether this kind of mini-psychotherapy of discussing the patient's emotions eventually makes any difference in their actual quality-of-life or treatment behaviours. Moreover, as every physician knows, discussing a patient's emotions takes time but is not usually reimbursed. It seems plausible though to assume that patients who are unsatisfied and distrustful will look around for a new doctor or avoid medical care altogether, while satisfied, trustful patients are more likely to seek further care from their doctor in the future as needed. Furthermore, patients who are satisfied and trustful of their doctor will recommend him or her to their family, friends, co-workers and neighbours. So even though discussing a patient's emotions takes extra time that remains unbillable, it makes good sense to do it. And we believe it enables physicians to provide better quality health care to their patients.

Although the framework of medical care does not normally allow a physician to provide the patient a half-hour psychotherapy session, it is not difficult to ask a few basic questions during the course of a 10-min visit and exam. How is CU disrupting their daily lives (sleep, work, socializing, sex, etc.)? How is it making them feel emotionally (e.g. annoyed, frustrated, embarrassed, angry, ashamed, etc.)? Are they feeling 'worried' (anxiety)? Are they feeling 'down' (depression)? Are they

feeling tense or achy (somatoform disorder)? Having this quick but crucial conversation with CU patients enables the physician to identify hidden problems and raises the satisfaction and trust of the patient.

Summarizing, CU has a substantial impact on patient QoL. Treatment guidelines (1–3) recommend second-generation antihistamines as first-line treatment, but only two-thirds of our respondents reported taking any kind of prescription medication for their CU when they experience outbreaks. Physicians should remain aware of the need for patient education about treatment. When a physician talks with a CU patient about how he or she is feeling, this is highly likely to raise satisfaction with treatment and trust in the physician. Patients who are satisfied with treatment and trust their physician are presumably more likely to continue coming to their doctor for treatment when needed.

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