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ATTENTUS, a German online survey of chronic urticaria patients highlighting the burden of disease, unmet needs and real-life clinical practice

Short title: An online survey of chronic urticaria patients highlighting unmet clinical needs

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Research Letter:

Chronic urticaria (CU) is a common recurrent skin disorder that can strongly impact quality of life,^{1,2,3} sleep and emotional well-being.^{4,2,5} The spontaneous form occurs without any specific triggers.⁶ Most previous publications report on patients treated at specialized centres, which tend to suffer from severe disease, and may not reflect the average patient.^{7,8} Thus, it is of major interest to investigate patients with CU in a real life setting. The ATTENTUS online survey recruited participants purely through online banner advertising which asked, “Do you suffer from chronic urticaria and would you like to participate in an online survey in order to help increase the knowledge of this disease?” It was designed to obtain self-reported patient data on the real-life impact of CU and current use of the health care system in Germany. Participants filled out a 30-item survey using a six-level Likert scale, i.e. 1 (not impaired at all) to 6 (extremely impaired), between August and November 2014.

A total of 17,508 participants completed this survey in only 12 weeks. The results presented here are *only* from the 9,055 participants who had received a diagnosis of CU by a physician. Similar to published data, patients were predominantly female (80.4% vs. 19.6%)^{9,10} and the mean age of CU onset was 26.7 ($\pm$ 14.1, standard deviation [SD]) years, confirming reports that CU develops mostly between 20 and 40 years of age.^{11,12} Participants had been affected by CU on average 11.5 ($\pm$ 10.8 SD) years.

Approximately one third of participants reported that their CU symptoms ‘affect’ or ‘extremely affect’ their daily lives (scores of 5 or 6, see Figure 1), and of these, 38.1 % reported continuous symptoms throughout the year. The ATTENTUS survey exposed a large proportion of CU sufferers that has apparently given up on visiting their doctor. Only 40% of participants who were symptomatic at the time of the survey were in physician care; furthermore, 74% of all participants with a CU duration of 15 years

or longer had stopped consulting a physician, resigning themselves to self-treatment, or simply living with their condition. Over one third of participants who suffered continuously throughout the year were not under a doctor's care (see Table 1) because they felt their doctor was unable to help them (53.8%), and they knew how to treat CU symptoms themselves (42.9%). Most participants had seen, at one time or another, a general practitioner (57.2%) and/or dermatologist (86.0%) and 41.5% had been treated in a clinic. However, when asked how well their symptoms were actually controlled with medication, 16.6% stated that their medication had little or no effect at all on symptom control, with an additional 36.5% indicating that their symptoms were insufficiently controlled.

Over half the participants stated that they had been prescribed cortisone products for their CU, but importantly, this did not appear to improve overall ratings in daily activity scores.

From the ATTENTUS survey, we conclude that in Germany, CU is uncontrolled in many patients. Most participants were unsatisfied with the medical treatments they received, and some who experienced severe symptoms found it difficult to control their CU, even with medication. The ATTENTUS survey exposed a large proportion of CU sufferers who has apparently given up on visiting their doctor to discuss current impairments, and instead, attempt to self-treat their condition. The burden was often felt to be higher retrospectively, suggesting that CU patients seem to develop 'coping strategies' during their episodes, recalling it to be worse in the past and not visiting a doctor when symptoms are present.

Importantly, our results also indicate that a highly burdened CU population exists outside of specialized centres, but may not be visible as such because a substantial proportion have stopped seeking their doctor's help.

Limitations of the ATTENTUS survey include the participant selection bias and whether this is a representative sample of CU patients as the survey was only accessible to those with internet access. Also, because this survey invited all individuals with CU to take part, those with the most active symptoms are more likely to have responded compared with those whose symptoms are well controlled. Additionally, a bias may have been introduced when recalling past information such as treatments received and effect on daily activities.

In light of the available International EAACI/GA²LEN/EDF/WAO Guidelines⁶ for the treatment of urticaria, the ATTENTUS survey raises the question of whether doctors are fully aware of the recommended therapy guidelines that aim to achieve a 'symptom free patient' in most cases.

The ATTENTUS survey is the first of its kind to investigate the burden of CU purely from the patients' perspective and has highlighted important findings in relation to the unmet clinical needs of CU patients. Better awareness of the burden of disease and available treatment options are needed and may help to improve real life patient care.

Figures

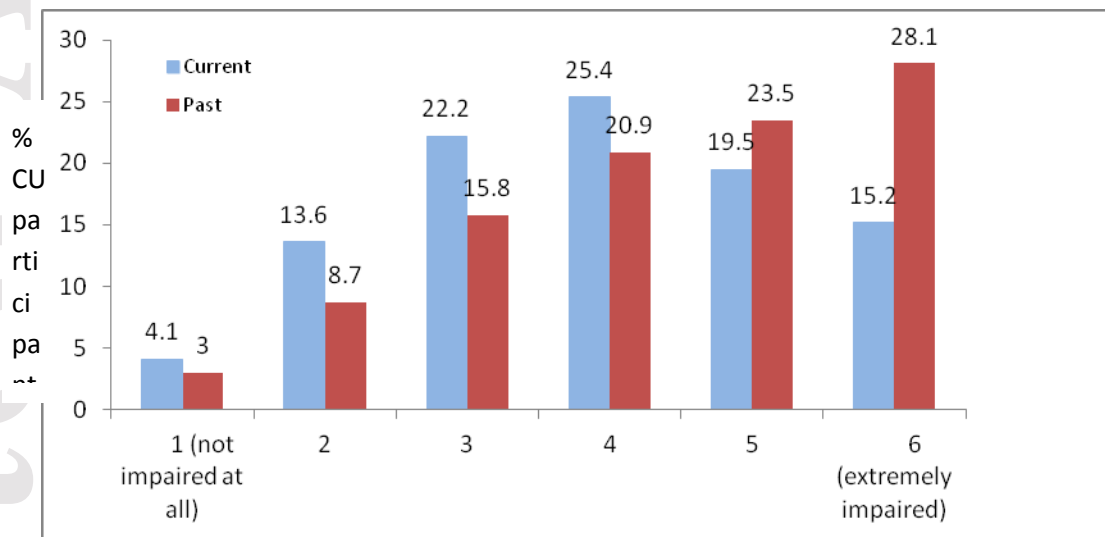


Figure 1: Impact of CU symptoms on work and leisure activities

Participants were asked the following question: Symptoms such as those of urticaria can impair affected persons more or less severely in everyday life. How strongly do you feel *impaired by urticaria symptoms at this time* at work and during leisure times OR how strongly did you feel impaired by urticaria symptoms at work and during leisure times *when you were last affected by urticaria symptoms*? Please respond using a scale from 1 (= not impaired at all) up to 6 (= extremely severely impaired).

Length of time affected (months)	Currently seeing a doctor % (n)	Not currently seeing a doctor % (n)
< 1	5.6 (168)	13.6 (822)
1 – 3	15.9 (476)	20.7 (1252)
4 – 6	17.3 (517)	15.4 (935)
7 – 11	17.4 (522)	15.1 (917)
12	43.8 (1311)	35.2 (2135)

Table 1: Average length of time in a year participant is affected by CU symptoms stratified by whether or not a doctor is seen

Participants were asked: Are you or were you receiving medical treatment for the already described urticaria symptoms? 1/ Yes, I am currently receiving medical treatment, 2/ No, I am currently not receiving medical treatment, but used to see a doctor for it or, 3/ No response. The no response field was 0% so has been excluded from the table.

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