

Cost-intensive, time-consuming, problematic? – How physicians in private practice experience the care of urticaria patients

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Summary

Background: Urticaria is a common and frequently debilitating disease. Nevertheless, there are only few studies examining the situation of urticaria patient care.

Patients and Methods: In this cross-sectional study, we surveyed dermatologists, pediatricians and general practitioners in the practice setting regarding the epidemiology, situation of care as well as the perception of their patients with chronic spontaneous urticaria.

Results: 776 data sets were available. The results show a high frequency of consultations due to chronic spontaneous urticaria. Most of the patients were reported to suffer moderately to severely and to have had history of disease of well over one year. The pediatricians indicated fewer diseases and shorter courses. The majority of participants stated that the time and cost spent on care, as well as the frequency of follow-up visits, are above average. In addition, chronic spontaneous urticaria patients were reported to be a group with a strong emotional burden and high expectations as well as a group that is difficult to satisfy and hard to guide. Only a small minority of physicians rated patient satisfaction with current treatment options and therapy success as high.

Conclusions: Chronic spontaneous urticaria plays an important role in daily practice. Problems are reported on various areas of care. Resolving these problems presents a major challenge and is crucial for improving the quality of patient care.

Introduction

Urticaria is one of the most common skin diseases occurring worldwide. About one in five people will experience a urticarial episode during the course of his or her lifetime [1–3]. Current guidelines distinguish spontaneous forms of urticaria (acute and chronic) from inducible, physical urticaria (e.g., urticaria factitia, pressure urticaria, cold urticaria) and other forms of urticaria (e.g., cholinergic urticaria) [4]. While acute, spontaneous urticaria often lasts only a few days or weeks, and is generally manageable with short-term symptomatic therapy, chronic spontaneous urticaria (csU) and

chronic inducible forms are often a completely different matter. The approved standard therapies are often unable to adequately control the disease [5]. Often, no cause is identified and thus causal therapy is performed in only a minority of patients [6–8]. Several recent studies have shown that csU is associated with a severely impaired quality of life [9–12]. Not only is the level of impairment one of the highest compared with other skin diseases [13], it is also comparable to serious internal diseases such as severe coronary heart disease [9]. Recurrent and often severe pruritus (and its sequelae) is one important factor. In addition,

the unpredictability of urticarial episodes as well as the disfigurement and respiratory distress associated with angioedema also contribute to an impaired quality of life and considerable psychological distress [9].

Despite the large number of affected patients, there are relatively few studies on the duration and severity of csU [5]. Most of the published data are from tertiary care facilities and thus only represent the everyday situation in practice settings to a limited extent. In addition, little is known about the related frequency of doctors' visits or the real-life situation of care and the motivation on

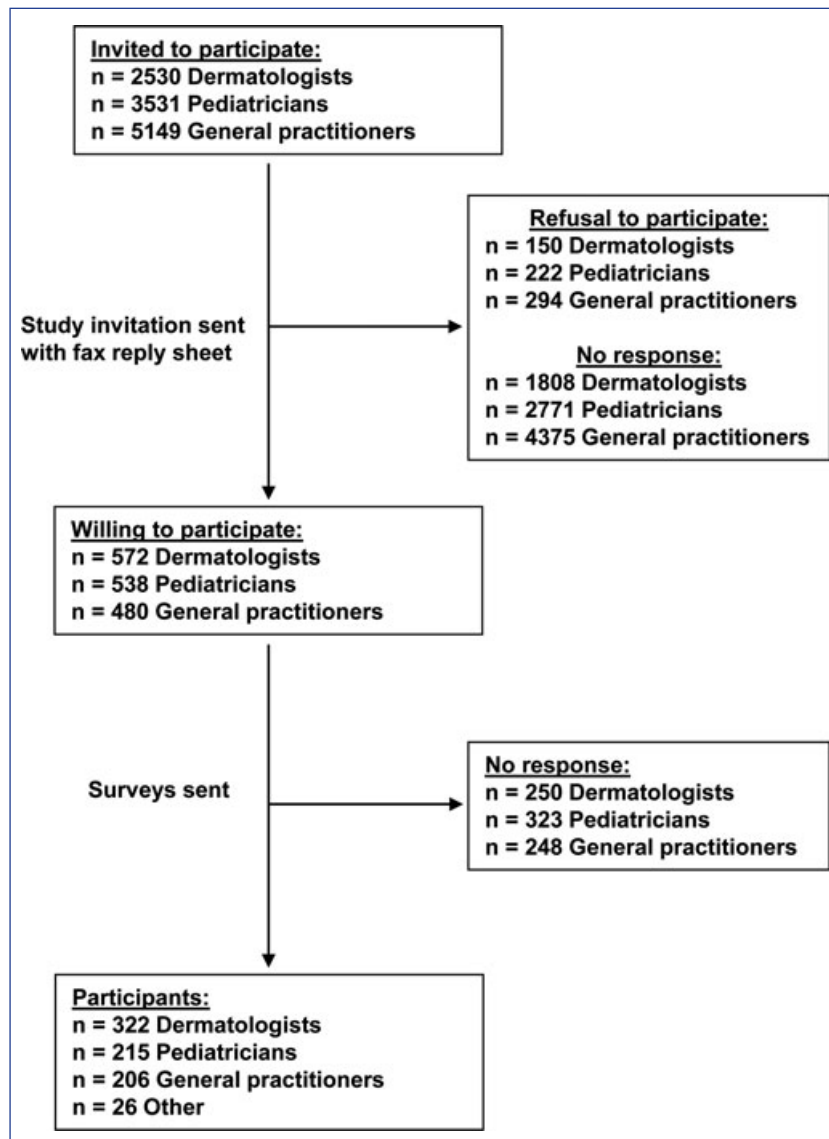


Figure 1: Flow chart – study course and recruitment.

the part of treating physicians. In light of increasingly limited financial resources, such data are crucial for identifying undesirable developments and ensuring high quality care.

The present study surveyed 776 physicians in Germany on diagnosing and treating urticaria patients. The main objective of the study was to document the care situation at present. In addition to questions on the frequency of visits, disease severity and duration, the survey also included questions on the economic aspects of care and the influence of health insurers. There were also questions concerning the guiding of patients, their expectations, emotional burden, and satisfaction as well as on the motivation of physicians.

Materials and methods

We contacted the majority of private practice physicians in Germany – dermatologists ($n = 2\,530$), pediatricians ($n = 3\,531$), and 5 149 general practitioners - in writing between February and April 2009 and asked whether they would be willing to participate in the study. Physicians could respond by indicating on the included fax page whether they wished to participate or not. Those who wished to participate ($n = 1\,590$) were then sent a survey containing 32 questions. Figure 1 shows the recruitment procedure. Reasons for non-participation were not documented.

The survey questions were compiled by a team of experts after thorough search of the literature (including guideline

recommendations, implementation of guidelines, patient satisfaction, prevalence, course, diagnosis, treatment, co-morbidities, disease burden, care and costs of urticaria). A pre-test of final questionnaire was then performed for comprehensibility and user-friendliness (11 dermatologists, 11 pediatricians, and 10 general practitioners). Topics included in the survey include information on the participants and their practices, urticaria patients, diagnosis, therapy, reality of care, and the perceptions of urticaria patients compared with other patients in the same practice. All participants were requested to fill out the questionnaire in full. The raw data from the returned surveys were then recorded, reviewed, and analyzed using MS-ACCESS, MS-EXCEL and SPSS 17. The present publication focuses on the numbers of urticaria patients being treated by physicians in private practice, disease course and severity, referrals, experience with recourse claims, physician motivation, and an assessment of the care situation and patients. Additional results from this study, such as further data on the study population as well as the diagnostic procedures and treatment used, also in comparison with current guidelines, will be published elsewhere [14]. The actual survey questions are available upon request. Participants received 50 Euros for completion of the 10-page survey.

The data were first analyzed descriptively. Given that one of the main goals of the study was to document the current care situation, including any differences between disciplines, we also performed explorative comparative statistical analyses comparing the different specialties in regard to the number of affected patients, disease courses, care situation, patient satisfaction, experience with recourse claims, and motivation. We performed the Pearson's chi-squared test and the Mann-Whitney U test.

Results

Participant population*

(*Author's note: some of the data reported here on the participant population are also published elsewhere due to methodological reasons [14].)

A total of 776 questionnaires were available for analysis (surveys from 49 % of participants, 7 % of all physicians originally contacted). Of these, 322 (43.0 %) were submitted by dermatologists, 215 (28.7 %) by pediatricians, and

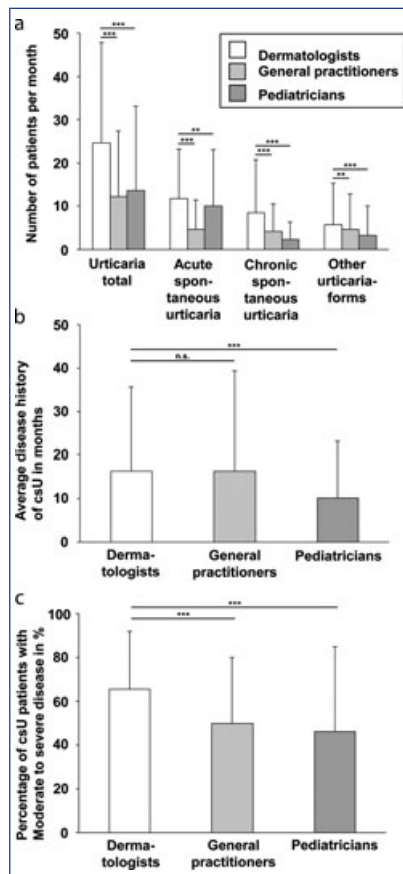


Figure 2: Urticaria often leads to consultations and frequently has a long and intense course. (a) The participants were asked to provide the number of urticaria patients per month. Other urticaria subtypes were further defined as “e. g., physical urticaria subtypes, cholinergic urticaria, contact urticaria.” The column “urticaria total” represents the results of a separate question and not the summation of the other response options. The results are presented as mean number $\pm$ SD; * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$ (Mann-Whitney U test). (b) The participants were asked to estimate the mean overall disease duration of chronic spontaneous urticaria (csU) and (c) the proportion of csU patients with mild, moderate and severe disease activity. The results are presented as mean proportion $\pm$ SD; ** $p < 0.01$, *** $p < 0.001$, n.s. = not significant (Mann-Whitney U test).

206 (27.5 %) by general practitioners. Twenty-six participants (3.5 %) either belonged to other specialties (e.g., internal medicine) or did not list their specialty. The average age of participating doctors was 50.3 ± 7.9 years. 39.9 % were women. Almost all respondents were specialists (96.4 %), and the majority had been in practice for less than 20 years (64.6 %). 41.8 % said they were located in a rural area, 38.7 % in an urban area, and 19.2 % in a large city. The 16 German states were represented roughly equally. As could be expected,

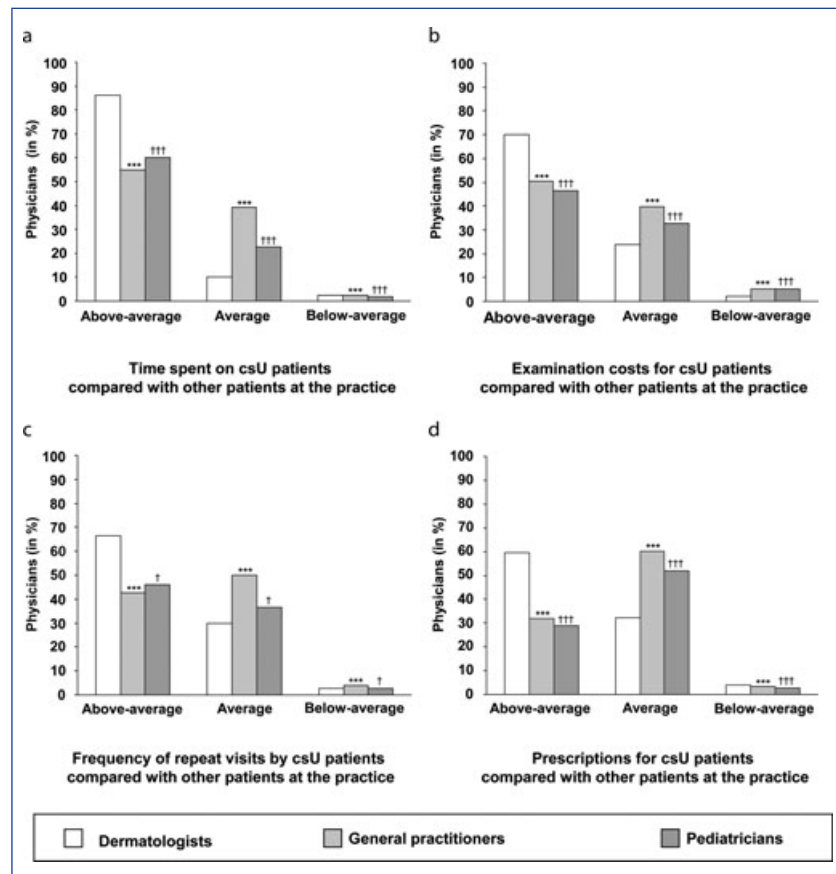


Figure 3: Care for patients with chronic spontaneous urticaria (csU) requires high resources. The participants were asked to compare patients with csU with their other patients in terms of (a) expenditure of time, (b) drug prescriptions, (c) examination costs (e. g., laboratory) and (d) frequency of follow-up visits. The results are expressed as physicians in percent who chose the respective answer option. Comparison of dermatologists vs. GPs: *** $p < 0.001$ (chi-squared test). Comparison of dermatologists vs. pediatricians: † $p < 0.05$, ††† $p < 0.001$ (chi-squared test). No data were provided for (a) by 0.9 % of dermatologists, 3.4 % of general practitioners and 15.3 % of pediatricians, for (b) by 4.0 % of dermatologists, 4.4 % of general practitioners and 15.8 % of pediatricians, for (c) by 0.9 % of dermatologists, 3.4 % of general practitioners and 14.4 % of pediatricians, for (d) by 4.0 % of dermatologists, 4.4 % of general practitioners and 16.3 % of pediatricians.

those regions with the highest populations also submitted the largest number of data sets. Bavaria: 136 (17.5 %); North Rhine-Westphalia: 135 (17.4 %); and Baden-Württemberg: 112 (14.4 %). The data regarding average age, sex distribution, and regional distribution of the participating doctors largely concur with the data from the German Medical Society (Bundesärztekammer) (Ärztestatistik 2009) [15]. The data on the distribution of participants to the different regions in Germany are also in agreement with general population data from the German Federal Office of Statistics [16].

Consultations due to urticaria are common
The number of urticaria patients treated per month is shown in Figure 2a. Dermatologists saw significantly larger numbers of urticaria patients (24.6 ± 23.3) than did

general practitioners (12.2 ± 15.2) and pediatricians (13.6 ± 19.6) (all physicians: 17.8 ± 20.8). Patients with acute spontaneous urticaria and csU were treated in roughly equal numbers by dermatologists as well as by general practitioners (dermatologists 8.5 ± 12.2 and 11.7 ± 11.5 ; general practitioners 4.2 ± 6.4 and 4.7 ± 6.7). Among pediatricians, patients with acute spontaneous urticaria (10.1 ± 13.0) were much more common than patients with csU (2.3 ± 4.0).

Chronic spontaneous urticaria often has a severe, protracted course

When asked about the duration of disease among patients with csU, on average dermatologists and general practitioners reported (24.6 ± 23.3 and 16.4 ± 22.9 months) longer courses than did pediatricians (10.2 ± 12.9 months,

Table 1: Recourse claims of health insurances have an impact on the care of chronic spontaneous urticaria (csU) patients. The participants were first asked if they already had experienced recourse claims due to prescribed therapies in csU patients. All physicians who chose “yes” were then asked if these had an impact on their therapeutic procedures. In addition, all participants were asked if recourse claims and their impact on the treatment habits lower the quality of care. Comparison of dermatologists vs. general practitioners and dermatologists vs. pediatricians were carried out using the chi-squared test.

Question	Specialty	Yes	No	No response	Significance
Have you been confronted with one or more recourse claims by health insurers related to the treatment of chronic spontaneous urticaria?	Dermatologists	18.9 % (n = 61)	78.3 % (n = 252)	2.8 % (n = 9)	p < 0.001
	General practitioners	6.3 % (n = 13)	91.3 % (n = 188)	2.4 % (n = 5)	
	Pediatricians	2.8 % (n = 6)	87.4 % (n = 188)	9.8 % (n = 21)	p < 0.001
If you answered “yes” to the above, did this influence later treatment behavior?	Dermatologists	70.5 % (n = 43)	27.9 % (n = 17)	1.6 % (n = 1)	n.s.
	General practitioners	61.5 % (n = 8)	23.1 % (n = 3)	15.4 % (n = 2)	
	Pediatricians	66.7 % (n = 4)	33.3 % (n = 2)	0 % (n = 0)	p = 0.005
In your opinion, does this compromise the quality of care of patients?	Dermatologists	34.8 % (n = 112)	10.2 % (n = 33)	55.0 % (n = 177)	n.s.
	General practitioners	28.2 % (n = 58)	11.7 % (n = 24)	60.2 % (n = 124)	
	Pediatricians	20.9 % (n = 45)	12.6 % (n = 27)	66.5 % (n = 143)	p = 0.022

Figure 2b). The difference between dermatologists and pediatricians was statistically significant ($p < 0.001$). Dermatologists reported that the percentage of csU patients with moderate to severe disease was on average 65.5 %. This is significantly higher than the figures reported by general practitioners (49.8 %) and pediatricians (46.1 %) (Figure 2c).

Caring for patients with chronic spontaneous urticaria requires significant resources

Nearly two-thirds of all participants (69.3 %) reported that the care of patients with csU was “more time-consuming than average” (Figure 3a). Among dermatologists this figure was 86.3 %. In addition, the majority (57.0 %) of respondents said that examination costs were “more of a budgetary problem than average” (Figure 3b) and the number of repeat visits was “higher than average” (53.4 %, Figure 3c). Dermatologists in particular (59.6 %) said that prescriptions were “more of a budgetary problem than average” while the same was reported by only 32.0 % of general practitioners and 28.8 % of pediatricians (Figure 3d).

On the question of the economic interest of csU patients for private practices, the majority of dermatologists (59.3 %) said they were of “less interest than average.” The same was reported by 31.6 % of general practitioners and 33.0 % of pediatricians (7.0 % of doctors did not respond). The differences between dermatologists and general practitioners as well as between dermatologists and pediatricians were in each case statistically significant ($p < 0.001$).

Recourse claims by health insurers influence the care of patients with chronic spontaneous urticaria

A total of 10.4 % of respondents reported having been confronted with recourse claims related to treating csU. Dermatologists were significantly more often affected than were general practitioners or pediatricians (Table 1). The overwhelming majority of affected physicians reported that the experience influenced their treatment practices and many participants felt that this was associated with a decline in the quality of care, although the majority did not specify further (Table 1).

Care of patients with chronic spontaneous urticaria is challenging

The majority of doctors (72.4 %) rated the emotional burden of csU patients as severe (Figure 4a). Nearly two-thirds of participants (63.3 %) described patient expectations as high (Figure 4b), 41.6 % found it difficult to satisfy these patients (Figure 4c) and 64.9 % of respondents said that guiding csU patients is difficult (Figure 4d). In addition, the majority of doctors (54.0 %) said an associated psychological burden (e.g., accompanying depression) occurs “more often than average” in patients with csU. In each instance, a significantly larger number of dermatologists rated the characteristics in question as “strong”, “high”, “difficult”, or “more often than average.”

Only a small minority of participants reported a high level of satisfaction with the current options for treating csU patients (5.7 %) or with treatment success (5.8 %), while nearly one-fourth of doctors each reported a low level of satisfaction with each (27.4 % and 23.1 %) (Figure 5a, b).

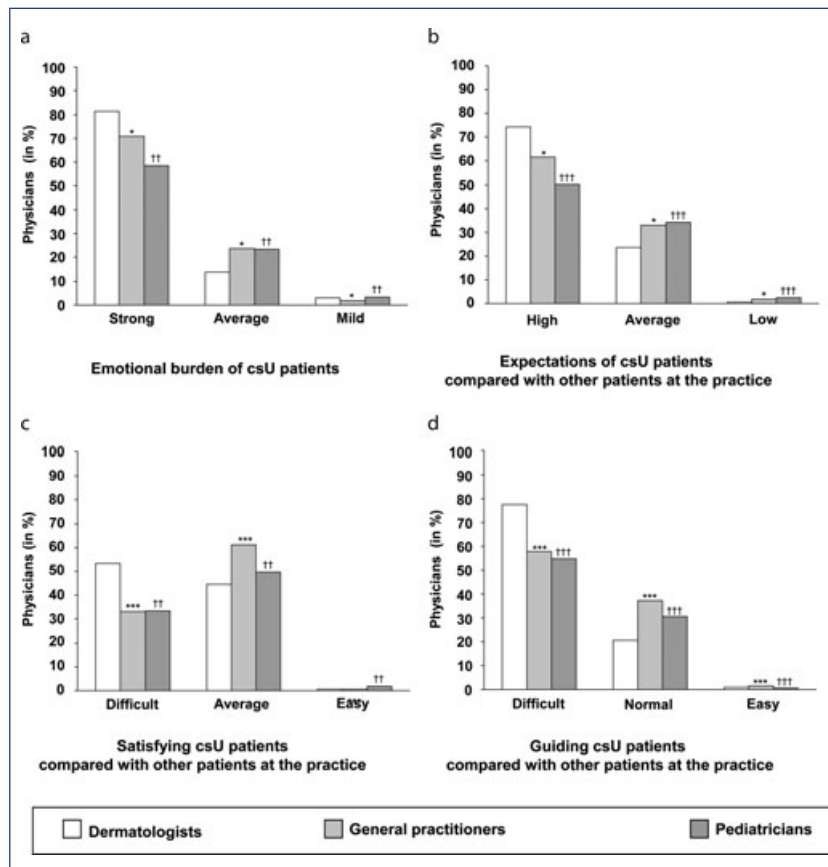


Figure 4: Care of chronic spontaneous urticaria (csU) patients is challenging. The participants were asked to estimate (a) the emotional burden of patients with csU. In addition, the physicians were asked to compare patients with csU with their other patients in terms of (b) expectations, (c) satisfaction and (d) guidance. The results are expressed as physicians in per cent who chose the respective answer option. Comparison of dermatologists vs. general practitioners: * $p < 0.05$, *** $p < 0.001$ (chi-squared test). Comparison of dermatologists vs. pediatricians: †† $p < 0.01$, ††† $p < 0.001$ (chi-squared test). No data was provided for (a) by 1.9 % of dermatologists, 3.4 % of general practitioners and 14.9 % of pediatricians, for (b) by 1.6 % of dermatologists, 3.4 % of general practitioners and 13.5 % of pediatricians, for (c) by 1.2 % of dermatologists, 5.3 % of general practitioners and 14.9 % of pediatricians and for (d) by 0.9 % of dermatologists, 3.4 % of general practitioners and 14.0 % of pediatricians.

The motivation for caring for patients with chronic spontaneous urticaria is average to good

The majority of respondents (84.9 %) described their motivation to care for csU patients as average or above-average (Figure 6). In response to the question as to how many of their own csU patients had been referred to a hospital or special urticarial consultation, physicians reported an average rate of 31.3 %. The percentage reported by dermatologists was significantly lower (dermatologists 21.5 % vs. general practitioners 39.2 % [$p < 0.001$], vs. pediatricians 40.0 % [$p = 0.001$]).

Discussion

Little is known about the reality of the care of urticaria patients in private practice. The results of the present survey confirm the high number of physician

visits due to urticaria and thus its importance in everyday practice for physicians. The results also indicate deficiencies on various levels of patient care.

Compared with other specialists, the dermatologists surveyed not only treated more patients with csU, but also a larger number of patients with moderate-to-severe disease. This is presumably due to selection, as, compared with other specialists dermatologists often become involved in treatment secondarily. Generally speaking, however, urticaria patients represent a significant portion of patients among all specialties. The data reported by pediatricians are especially relevant. Although the incidence and prevalence of urticaria among children has not been studied as thoroughly as among adults [17], there is no doubt that children are often also affected

[17–19]. The results of the present study confirm this and also show that among pediatricians, patients with acute spontaneous urticaria are much more common than are patients with csU. This may be due to the fact that acute spontaneous urticaria has a much lower tendency to become chronic in children. Also, pediatricians reported shorter average durations of csU than did general practitioners and dermatologists. These results concur with studies on the distribution of pediatric urticaria. Small hospital samples have shown that children are less often affected by csU and more often by acute spontaneous urticaria [20, 21].

Physicians reported that the care of csU patients is time-consuming, expensive, and associated with repeated visits. The majority of respondents also described economic interest of treating csU patients as less than average. These results suggest that related expenses, in terms of time and money, are not adequately compensated. Key factors for the successful treatment of urticaria patients are the taking of a careful patient history and performing a thorough diagnostic assessment of potential causes. These take time and money. It should also be noted that more than 10 % of all respondents – among dermatologists, nearly one in five – have already been confronted with recourse claims related to the treatment of urticaria, sometimes with consequences for the choice of treatment procedures.

These factors notwithstanding, the treatment of csU patients is seen as a challenging. In addition to a considerable emotional burden, private practice physicians report high expectations among patients and only average satisfaction with current therapy options and treatment success. Perhaps as a result of this, guiding affected patients is seen as difficult. Explanations include the fact that csU patients have a severely impaired quality of life [9–12] often have accompanying psychological disorders [22–25], can be rarely treated causally [6–8] and symptoms are often untreatable with standard antihistamine therapy [5]. A recent study showed that many urticaria patients only take their antihistamine medication as needed rather than using it continuously [26]. Taking antihistamines only as needed limits the effectiveness of treatment [27]. Eliciting a thorough patient history and carefully advising the patient could

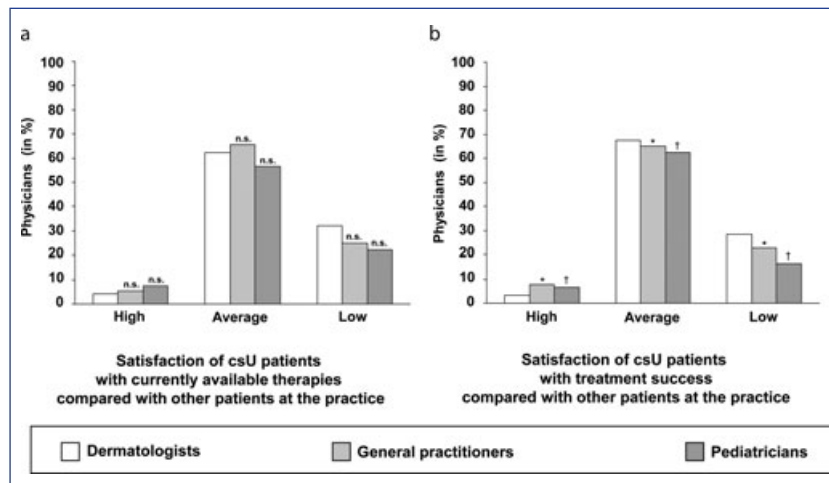


Figure 5: The satisfaction of chronic spontaneous urticaria (csU) patients with the current therapeutic options and the therapeutic success is fair. The participants were asked to compare patients with csU with their other patients in terms of (a) satisfaction with the current therapeutic options and (b) satisfaction with the current therapeutic success. The results are expressed as the percentage of physicians who chose the respective answer option. Comparison of dermatologists vs. general practitioners: * $p < 0.05$, n.s. = not significant (chi-squared test). Comparison of dermatologists vs. pediatricians: † $p < 0.05$, n.s. = not significant (chi-squared test). No data were provided for (a) by 1.2 % of dermatologists, 4.4 % of general practitioners and 13.5 % of pediatricians and for (b) by 0.9 % of dermatologists, 4.4 % of general practitioners and 14.9 % of pediatricians.

help improve treatment success and contribute to patient satisfaction.

Given the complexity of the problems in caring for csU patients, it is surprising that most doctors did not report being less motivated than average. Yet on the other hand, there is a high rate of referrals to clinics or specialized units which may be seen as a further indication of the difficult situation in the outpatient care of urticaria patients.

When interpreting the data and analyzing their significance, it is important to take into account the limitations of the results and their generalization. The characteristics of the participant population are largely comparable with the data from the German Medical Association (Ärzte-statistik) [15] and the population distribution reported by the German Federal Office of Statistics [16]. The quality of the data is further supported by their concurrence with findings from epidemiological studies on the characteristics of csU patients, such as average age and sex distribution [4, 28–30]. Nevertheless, in any voluntary survey study, there is selection of the physician sample (selection bias) which is difficult to control for. It is conceivable, for example, that study participants are more motivated and thus their evaluation of various problem areas is milder than it would be among those doctors who refused to participate. It is also possible that doctors with a special

interest in urticaria would be more likely to participate, which would negatively affect the representativeness of the results. The response rate was modest, at nearly half of all doctors who said they were willing to participate and 7 % of those originally contacted. Reasons for participation or non-participation were not recorded. It should also be recalled when interpreting the data that the results are based on physician assessments rather than a retrospective study of documented patients. In addition, studies have shown that doctors' evaluations of patients' treatment expectations, the usefulness of various therapies, disease severity, or patient satisfaction, may diverge from the patient's own views [31–33], although this is not necessarily the case [34]. Still, based on our own experience, we believe that the results are largely applicable to the actual situation in the specialties studied.

Conclusions

The results presented here demonstrate the importance of urticaria, in particular csU, in the everyday private practice and reveal various problems in patient care on several levels. These include economic aspects, doctor-patient interaction, patient satisfaction with treatment options and success, and external pressure on physician decision-making. Among the specialties studied, dermatologists appear to be most strongly affected.

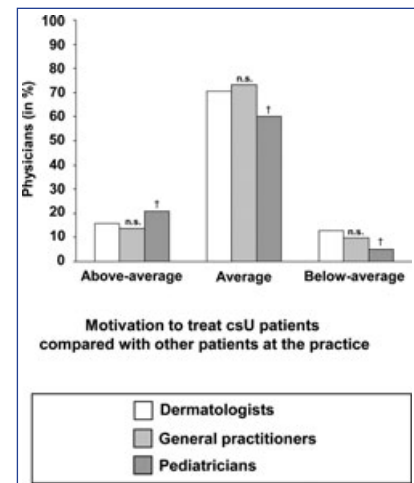


Figure 6: The motivation of physicians to care for chronic spontaneous urticaria (csU) patients is average. The participants were asked to rate their motivation to care for patients with csU in comparison to their other patients. The results are expressed as the proportion of physicians in per cent who chose the respective answer option. Comparison of dermatologists vs. general practitioners: n.s. = not significant (chi-squared test). Comparison of dermatologists vs. pediatricians: † $p < 0.05$, n.s. = not significant (chi-squared test). No data was provided by 0.9 % of dermatologists, 3.4 % of general practitioners and 14.0 % of pediatricians.

Finding solutions to these problems is important for improving the quality of care of urticaria patients in the future.

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Conflict of interest

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