

Digital Health Behavior in Chronic Spontaneous Urticaria: Internet and Social Media Use Patterns

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ABSTRACT Introduction: Chronic spontaneous urticaria (CSU) is a prevalent dermatological condition leading to frequent visits to primary care, emergency departments, and dermatology clinics worldwide. Its chronic relapsing nature, accompanied by angioedema, shortness of breath, and intense pruritus, drives patients to seek information and treatment.

Objective: This study aimed to investigate CSU patients' Internet usage habits, including their search terms, trusted sources, and whether they share this information with their physicians.

Methods: A survey was conducted among 80 patients at a tertiary hospital's urticaria outpatient clinic. Data collected included sociodemographic characteristics, urticaria activity scores, dermatology life quality indexes, and Internet and social media usage patterns related to CSU.

Results: Of the 80 patients, 73.8% had researched CSU online, with significantly higher usage among younger, single patients with lower educational levels and shorter disease duration. Google was the most used platform (84.7%), followed by Instagram and YouTube (25.4% each). General information about CSU was the primary search term (76.3%). Notably, 21.3% attempted to contact doctors via social media, a behavior less common among patients using omalizumab. Approximately 75% did not share their findings with their physicians. Additionally, 58.8% expressed a desire for dermatologists to provide more online information about CSU.

Conclusions: CSU patients frequently research their condition online but often conceal this from their doctors. Attempts to contact physicians via social media were lower among omalizumab users, possibly due to regular follow-ups. Enhancing dermatological follow-up and online educational resources could improve patient engagement and treatment adherence.

Introduction

Urticaria is one of the common reasons for visits to primary healthcare facilities, emergency departments, and dermatology clinics worldwide. It can occur in anyone, regardless of ethnicity or age, and is characterized by a sudden onset of red-pink, edematous, itchy papules and plaques known as wheals, which usually disappear within 24 hours without leaving any marks. If it lasts less than six weeks, it is classified as acute; if it persists longer, it is considered chronic. Patients who experience urticaria attacks at least twice a week for more than six weeks without any specific trigger are diagnosed with chronic spontaneous urticaria (CSU). CSU is more common in middle-aged and young women and is estimated to affect 1% of the global population [1]. The form triggered by specific stimuli such as heat, cold, pressure, or vibration is called chronic inducible urticaria [2]. CSU can occur alone or in combination with chronic inducible urticaria, complicating its treatment even further [3].

Angioedema, characterized by edema in mucous membranes such as eyelids, lips, and airways, accompanies 40–60% of CSU patients [4]. Recent studies have shown an association between CSU and several autoimmune diseases, including autoimmune thyroiditis, vitiligo, type 1 diabetes mellitus, and pernicious anemia. Additionally, metabolic syndrome and psychiatric disorders, particularly anxiety and depression, are considered comorbidities of urticaria [1].

In 25–75% of patients, CSU lasts longer than a year and follows a fluctuating course with relapses and remissions. The unpredictability of the onset, duration, and severity of attacks significantly impacts patients' quality of life [5]. Furthermore, factors such as the presence of angioedema, sleep disturbances due to nocturnal itching, and interference with school and work life contribute to a quality-of-life impairment that is equal to or greater than that experienced by patients with moderate-to-severe psoriasis, atopic dermatitis, asthma, and severe coronary artery disease requiring bypass surgery [6,7]. These reasons inevitably lead patients to research the disease online, which provides easy, widespread information access. In recent years, it has been shown that CSU patients use social media and other communication tools to connect with each other and gather information about the disease [8]. However, it is still unknown which social media platforms and search engines they use, what exactly they are searching for regarding the disease, or what they apply to themselves based on the information they obtain.

Objectives

This study aimed to investigate the Internet usage habits of CSU (chronic spontaneous urticaria) patients to learn about their disease, including what they search for, which

sources they trust, and whether they share this information with their treating physicians.

Methods

Patients

The study included 80 literate CSU patients over the age of 12 who were followed at the Urticaria Outpatient Clinic of the Dermatology Department at Istanbul Medeniyet University, Göztepe Prof. Dr. Süleyman Yalçın City Hospital between 08 June and 31 July 2023, and who agreed to participate.

Procedure

Approval of the study was obtained from the Clinical Research Ethics Committee of Istanbul Medeniyet University, Göztepe Prof. Dr. Süleyman Yalçın City Hospital(07.06.2023/0367). The researchers prepared the questionnaire after reviewing the relevant literature. The physicians recorded information regarding the patients' clinical status and treatment. The patients completed the prepared questionnaire forms, including the Urticaria Activity Score (UAS) and Dermatology Life Quality Index (DLQI), without any time constraints. Patients were allowed to consult the researchers if they did not understand any questions on the forms.

Statistical Analysis

The data obtained in the study were analyzed using the SPSS IBM statistical software package. Descriptive statistics, frequencies, and percentages of the survey results are provided. The chi-square test was used to compare categorical data, while the independent samples t-test was used to compare quantitative data. Depending on the expected value <5 in cells and the lowest expected value, the appropriate p-value was chosen from Pearson chi-square, continuity correction, or Fisher's exact test. The Z-test was used in multicell tables to determine the differences between variables when comparing categorical data. ANOVA test was used to compare the means of more than two groups. Test results were evaluated at a significance level of $P < 0.05$. Since multiple choices could be marked in some questions, the total percentages exceeded 100%.

Results

Sociodemographic and Clinical Characteristics of Patients, Internet and Social Media Usage Habits

The study included 80 patients (58 females, 22 males); 72.5% were married, and 27.5% were single. Table 1 presents other demographic and clinical characteristics of the patients.

Twenty-five percent of the patients had previously used topical corticosteroids, 10% had used systemic

Table 1. Sociodemographic and clinical characteristics of patients.

	Minimum-Maximum	Mean ± SD
Age (years)	16-80	47,29±14.04
UAS7	0-12	6,85± 3,065
DLQI	0-24	9,93±8,203
Disease duration (months)	6-480	84,55±95,547
Incomepercentage (%)	35000TL ^and below 71.2%	Above 35000TL 26.2%
Education levelPercentage (%)	High school and below 73.8%	College and above 26.2%
	YES (%)	NO (%)
Employment status	47.3%	56.3%
Smoking	23.8%	72.6%
Alcohol consumption	6.2%	93.8%
Family history of urticaria	21.2%	78.8%
Antihistamine use	98.9%	1.2%
Omalizumab use	73.8%	26.2%

Abbreviations: UAS7: Last 7-day Urticaria Activity Score; DLQI: Dermatology Life Quality Index; TL: Turkish liras.

corticosteroids, and 98.8% had used systemic antihistamines for urticaria lesions. The proportion of patients currently using omalizumab was 73.8%. Except for one of these patients, all were also regularly using antihistamines.

It was observed that 50% of the patients used social media and the Internet regularly, 27.5% used them occasionally, and 22.5% did not at all. Furthermore, 46.3% stated that they regularly used the internet for research related to CSU, 27.5% used it occasionally, and 26.3% did not use it at all.

Among patients with a monthly income of less than 35000TL, the proportion of well-controlled patients with a UAS7 score of six or below (evaluated over the previous seven days) was 43.9%, whereas this rate was 78.3% among those with a monthly income of 35000TL or more ($P=0.005$).

No significant difference was found between the groups when comparing the rate of active Internet usage by sex and financial status categories. Table 2 presents the characteristics related to active Internet usage among patients.

Social Media and Internet Platforms Used by Patients to Research Their Disease and Contact Physicians

Of the patients in the study, 73.8% used the Internet and social media regularly or occasionally to research their disease. Table 3 shows patients' social media and Internet tools for research on CSU. The most used tool was the Google search engine, with 84.7%. The most frequently researched topic was general information about the disease (76.3%), followed by medications (61%), physicians (44.1%), and patient reviews (35.6%). The rate of searching for general information about the disease on the Internet was 69% among those using omalizumab, compared to 94.1% among those not using it ($P=0.048$).

The rate of patients wanting doctors to share more information online was 20.3% among omalizumab users and 47.6% among non-users ($P=0.034$). The rate of using Instagram for disease research was 35.7% among those receiving omalizumab treatment, whereas no patient in non-receiving omalizumab group used Instagram for this purpose ($P=0.003$).

Among the participating patients, 21.3% attempted to contact doctors via social media. The most common method was by phone (52.9%), followed by Instagram (41.2%). Other platforms used were Google (35.3%), doctor websites (35.3%), health websites (17.6%), and Facebook (5.9%), while no patient used Twitter for this purpose.

The rate of trying to reach doctors via Instagram was significantly higher among females (66.7%) than males (12.5%) ($P=0.05$). The rate of contacting doctors through their websites was 54.5% among those with a lower socioeconomic status, while none of the patients with a better socioeconomic status used this tool ($P=0.043$). Patients using omalizumab attempted to reach their doctors through the hospital (71.4%), whereas none of the other patients used this method ($P=0.05$).

Patient Perspectives on Communication with Doctors via Social Media

Of the participating patients, 16.3% believed that doctors contacted through social media were obligated to respond to patients' questions, 25% thought that doctors in private practice were obligated to respond, and 26.3% stated that although they were not obligated, they should respond as a courtesy; 64.7% of the patients trusted the answers provided by doctors on social media. However, 48.8% said they would not trust the response if they reached the doctor via a photo

Table 2. Internet and social media use by chronic urticaria patients.

	Yes	No	Sometimes	Total	P'
Sex	n (%)	n (%)	n (%)		
Female	29 (50%)	14 (24.1%)	15 (25.9%)	58 (100%)	0.796
Male	11 (50%)	4 (18.2%)	7 (31.8%)	22 (100%)	
Marital Status					
Married	24 (41.4%)	16 (27.6%)	18 (31%)	58 (100%)	0.023
Single	16 (76.2%)	2 (9.5%)	3 (14.3%)	21 (100%)	
Average age (years)	42.86±13.88	58.10±11.27	44.41±11.43	47.29±14.04	<0.001
Disease duration (months)	62.32±78.67	131.44±134.99	77.18±57.02	84.55±95.547	0.025
UAS7					
Well-controlled	2353.5%)	920.9%)	11 (25.6%)	43 (100%)	0.798
Mild	17 (45.9%)	9 (24.3%)	11 (29.7%)	37 (100%)	
Income level					
≤ 35000TL	2645.6%)	1628.1%)	15 (26.3%)	57 (100%)	0.165
> 35000TL	1460.9	28.7%)	7 (30.4%)	23 (100%)	
Educational level					
High school and below	2339%)	1830.5%)	18 (30.5%)	59 (100%)	0.002
College and above	17 (81%)	0 (0%)	4 (19%)	21 (100%)	

Abbreviations: UAS7, Last 7-day Urticaria Activity Score; TL: Turkish liras.

Table 3. Social media and Internet tools used for CSU research.

Active Internet Usage	Number	Percentage
Facebook	7	11.9
Instagram	15	25.4
Twitter	1	1.7
YouTube	15	25.4
Google	50	84.7
Patient Blogs	10	16.9

of their condition on social media, and 43.8% stated they would visit the doctor in person even if they received an answer online.

Social Media Research and Expectations Related to the Disease

Of the participating patients, 7.5% were members of a patient group related to urticaria on social media or the Internet; most of these members (66.7%) reported being part of WhatsApp groups on this topic.

Of the participating patients, 8.6% applied what they saw on the Internet to their disease management, while 25.4% asked their doctors about the research they conducted online; 84.7% stated that if the information they found on social media differed from what their doctor recommended, they trusted the information provided by their doctor, while 18.6% said they sought a second opinion from another doctor in such cases.

Of the participating patients, 16.3% reported watching health programs in the media regularly, while 61.3% watched them occasionally. Most patients (52.5%) expressed that realizing other CSU patients existed gave them relief; 38.8% stated that they liked seeing discussions about CSU and the attention given to the disease on these programs, while 12.5% mentioned that advertisements for medications or doctors were shown. The proportion of those who appreciated the importance given to the disease was significantly higher among females (48.3%) compared to males (13.6%) ($P=0.005$).

Recommendations to Dermatologists on Social Media Usage

The patients participating in the study suggested that if information about CSU is to be provided on the Internet and social media, it should only be given by dermatologists (58.8%) and that dermatologists should actively use the Internet (58.8%). They also recommended that dermatology associations should not allow incorrect individuals to share misinformation (48.8%), that more seminars (37.5%), promotional programs (32.5%), and patient education schools (28.3%) should be organized, and that dermatologists should share more information on this subject on the Internet (27.5%). The proportion of those who wanted to obtain information from seminars was 44.8% among females, whereas it was 18.2% among males ($P=0.038$).

Discussion

Of the patients in our study, 73.8% used the Internet and social media to research their CSU disease. This rate was statistically significantly higher among single patients, younger patients, those with a high school education or lower, and those with a shorter disease duration. The most used platform for researching the disease was the Google search engine (84.7%), followed by Instagram and YouTube, each at 25.4%. In multicenter studies conducted with patients with psoriasis vulgaris and acne vulgaris, the rates of researching their diseases on the Internet were similarly high, at 80.52% and 75.8%, respectively [9,10]. In these studies, acne vulgaris patients most frequently used Google, followed by Instagram and YouTube, whereas psoriasis vulgaris patients also used Google most frequently but used Facebook as the second most common platform. In another study where social media searches of acne vulgaris patients were recorded, Instagram was the most frequently used platform [11]. This situation was attributed to acne patients being, on average, younger, while psoriasis patients were older [9-11]. Our study sample also mainly consisted of young individuals (mean age 47.29±14.04 years). Therefore, younger people prefer Instagram more frequently, and YouTube, whose popularity has been increasing in recent years, is used more often in Internet research. The rate of using Internet for disease information was very high among singles (94.7%). Based on this finding, it can be concluded that individuals who receive emotional support in their relationships are less likely to turn to social media.

Furthermore, 74.6% of the patients did not ask their doctors about the information they found online, and 6.3% applied the information they obtained online to their disease. However, in conflicting information, 84.7% of the patients stated that they trusted the information they received from their doctor rather than what they saw on social media. These rates were similar to those found in studies conducted with other dermatological diseases [9,10]. This indicates that despite the growing influence of the Internet, physician-sourced information is still considered more reliable by patients and that the participants recognize the risk of misinformation on social media and the Internet. Therefore, the participants demanded that dermatologists and dermatology associations actively use the Internet to provide reliable information (58.8%), that only dermatologists should provide disease-related information (58.8%), and that misinformation sharing should not be allowed (48.8%).

It is known that females use Instagram more intensively, actively, and for networking purposes [12]. In our study, the rate of reaching out to doctors via Instagram was significantly higher among females (66.7%) compared to males (12.5%). In our study, patients most frequently searched for general information about their disease (76.3%). This was

followed by information about medications (61%), doctors (44.1%), and patient reviews (35.6%). Similar rates were found in studies conducted with acne vulgaris and psoriasis patients [9,10]. Medication-related searches were the most common in a study that focused solely on treatments [13].

In our study, patients who did not use omalizumab tended to seek general information about the disease. This may be because patients using omalizumab need to visit their doctors more frequently, making it easier for them to obtain information directly from their doctors and leading to better disease control.

The proportion of those who wanted to gain information from seminars was 44.8% among females, while it was 18.2% among males. Similarly, females were more pleased to see their disease discussed and given importance on media programs such as television (48.3% vs. 13.6%). This suggests that females not only seek information about their diseases but also prefer spending time with others who share the same condition. A study conducted with Crohn's disease patients found that participants were happy to be with people suffering from the same illness and to exchange ideas about their issues, which helped them feel less ashamed about their disease [14].

Half of the patients with poor financial status reached doctors through their websites, while none of the patients with good financial status tried this method. This finding may indicate that the group with poor financial status has more difficulty reaching doctors directly and therefore tries to contact doctors online.

Conclusions

It is a fact that the Internet, which is at everyone's fingertips and often allows us to access the information we want with a single easy click, provides patients with a wide variety of information about their diseases, the accuracy of which is questionable. As seen in previous studies on social media usage related to other dermatological diseases, patients conduct research on the Internet about their illnesses and try to reach out to doctors. CSU is a chronic disease with difficult management, and communication with the patient plays a significant role in disease management.

Since patients are aware that CSU is a chronic, difficult-to-treat, recurrent disease, the majority of them resort to this type of research method. Additionally, CSU patients report that their doctors should share more information about the disease on the Internet and social media and that dermatology associations should prevent the spread of misinformation. This situation shows that while the public has access to a wide variety of information on social media, they do not fully trust it and prefer to access accurate information from physician sources.

Our study indicates that dermatologists can indirectly contribute to raising patient awareness and proper management of CSU by being more active on social media platforms accessible to patients and increasing the presence of accurate information. Even though only a tiny portion of patients prefer information obtained from the Internet over information received from their doctor, this reveals the dangerous side of social media. Considering the misinformation on online platforms, competent individuals must provide the necessary information to better understand and manage the disease. Additionally, it has been determined that patients using omalizumab avoid misinformation on the Internet and obtain information from their doctors instead. This is explained by the fact that patients using omalizumab are regularly monitored by their doctors and have easier access to them.

The periodic dermatological follow-up process, in which dermatologists provide necessary explanations about the nature and course of the disease, and patients are consciously involved, will enhance adherence to treatment and ensure access to accurate information.

References

1. Gonçalo M, Giménez-Arnau A, Al-Ahmad M, et al. The global burden of chronic urticaria for the patient and society. *Br J Dermatol.* 2021;184(2):226-236. PMID: 32956489 DOI: 10.1111/bjd.19561.
2. Kaplan AP. Treatment of chronic spontaneous urticaria. *Allergy Asthma Immunol Res.* 2012;4(6):326-331. PMID: 23115728 DOI: 10.4168/aair.2012.4.6.326.
3. Aslan Kayıran M, Akdeniz N. Diagnosis and treatment of urticaria in primary care. *North Clin Istanbul.* 2019;6(1):93-99. PMID: 31180381 DOI:10.14744/nci.2018.75010
4. Maurer M, Houghton K, Costa C, et al. Differences in chronic spontaneous urticaria between Europe and Central/South America: results of the multi-center real World AWARE study. *World Allergy Organ J.* 2018;11:1-10.
5. Maurer M, Weller K, Bindslev-Jensen C, et al. Unmet clinical needs in chronic spontaneous urticaria. A GA2LEN task force report. *Allergy.* 2011;66:317-330. PMID: 21083565 DOI: 10.1111/j.1398-9995.2010.02496
6. O'Donnell B, Lawlor F, Simpson J, et al. The impact of chronic urticaria on the quality of life. *Br J Dermatol.* 1997;136:197-201. PMID: 9068731
7. Grob J, Revuz J, Ortonne J, et al. Comparative study of the impact of chronic urticaria, psoriasis and atopic dermatitis on the quality of life. *Br J Dermatol.* 2005;152:289-295. PMID: 15727641 DOI: 10.1111/j.1365-2133.2005.06385
8. Mondal H, Dhabal A, Mondal S, Podder I. Social Media and Urticaria - A Data Audit of Facebook®, LinkedIn®, and Twitter® Posts. *Indian J Dermatol.* 2024;69(1):106. PMID: 38572049 DOI: 10.4103/ij.d.ijd_112_23.
9. Aslan Kayıran M, Karadağ AS, Alyamaç G, et al. Social media use in patients with acne vulgaris: What do patients expect from social media? *J Cosmet Dermatol.* 2021;20(8):2556-2564. PMID: 34087036 DOI: 10.1111/jocd.14272.
10. Aslan Kayıran M, Karadağ AS, Oğuz Topal İ, et al. Habits of Using Social Media and the Internet in Psoriasis Patients. *Dermatol Pract Concept.* 2022;12(3):e2022143. PMID: 36159107 DOI: 10.5826/dpc.1203a143.
11. Tasoula E, Gregoriou S, Chalikias J, et al. The impact of acne vulgaris on quality of life and psychic health in young adolescents in Greece. *An Bras Dermatol.* 2012;87(6):862-869. PMID: 23197205 DOI: 10.1590/s0365-05962012000600007.
12. Riquelme HE, Rosa ER, Al-Thufery N. Instagram: its influence to psychologically empower women. *Inf Technol People.* 2018;31:1113-1134.
13. Yousaf A, Hagen R, Delaney E, et al. The influence of social media on acne treatment: a cross-sectional survey. *Pediatr Dermatol.* 2020;37:301-304. PMID: 31944359 DOI: 10.1111/pde.14091
14. Zhao J, Han H, Zhong B, et al. Health information on social media helps mitigate Crohn's disease symptoms and improves patients' clinical course. *Comput Hum Behav.* 2021; 115:106588.