





# Listening to Urticaria Patients Through Social Media: Analyzing the Impact of the COVID-19 Pandemic

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## ABSTRACT

**Objective:** Urticaria patients possess a significant demand for understanding their condition, a need that traditional patient-reported outcome measures fail to gauge accurately. This social media listening (SML) study aimed to assess the impact of urticaria on patients' expressions on various social media platforms (SMP).

**Materials and Methods:** Using keyword-based search, a social media data scraping tool was used to identify all publicly available social media posts on urticaria. The content was manually curated to analyze and map psychological aspects with descriptive statistics applied on aggregated findings. Results were compared as pre-COVID-19 period and COVID-19 period.

**Results:** Overall, 34242 content (8763 content by 5238 unique users in the pre-COVID-19 period and 25479 content by 14546 unique users in the COVID-19 period) about urticaria were identified. X (Twitter) was the most frequently used (44%) SMP. Itching (14383 content, 42%), redness (11348 content, 33%) and swelling (5314 content, 16%) were the most frequently posted distressing symptom. Common patient expressions of symptoms included “pain”, “getting bored”, “embarrassment”, and “helplessness”. Chemical cleaners (4553 posts) and stress/upset (4809 posts) were the most common causes of urticaria from the patients' perspective, in the pre-COVID and COVID-19 periods, respectively. Patients mentioned that treatment of urticaria is a long and tiring process, and often try to manage their urticaria by avoiding triggers.

**Conclusion:** Our SML analysis showed the severe emotional impact of urticaria on the patients. The COVID-19 pandemic influenced access to care and patient expression about the disease. Understanding these challenges is crucial for healthcare professionals and organizations aiming to effectively address and support individuals with urticaria.

**Keywords:** Urticaria, chronic spontaneous urticaria, social media listening, patient-reported outcomes, COVID-19

## INTRODUCTION

Urticaria is a common debilitating inflammatory skin disorder with up to 20% lifetime prevalence worldwide (1). Urticaria is classified based on its duration as acute urticaria ( $\leq 6$  weeks) and chronic urticaria (CU;  $> 6$  weeks) (2).

CU affects more than 1% of the world's population and may last for several years (2, 3). CU has a substantial burden on patients and society, markedly impairs the patients' quality of life, and can be severely debilitating (4). These effects of CU on patients should be assessed using patient-

reported outcome measures (PROMs) that evaluate disease activity, disease control and quality of life. Multiple patient-reported outcome measures have been developed for this specific purpose and have been validated in various languages (5).

However, studies have demonstrated that physicians who provide care to patients with CU often lack awareness of PROMs and do not regularly incorporate them into their practice (6). To overcome this barrier, increase compliance, and integrate patients with PROMs, a user-friendly platform was developed allowing patients to easily complete PROMs on their mobile devices (7, 8). Even though it is possible to effectively track patients' disease control, disease activity, and quality of life with this or other similar digital health tools, applications are not open to general interaction and only allow patient-physician interactions. Patients with CU have a high need for knowledge about their disease, in order to discover more about its causes, course, possible trigger factors, available treatment options, and prognosis. It has been shown that the majority of them have access to information and communications technologies (ICT), especially social media platforms (SMP) (9). They are interested in utilizing SMPs to receive information, consult with physicians, and communicate with other patients regarding their disease (10). Thus, these SMPs constitute a vast database of patient insights and experiences that are not possible to be measured by PROMs.

A social media listening (SML) study is a research method that focuses on analyzing information from SMPs to gain insights into various topics. It uses a systematic approach to collect, analyze, and interpret data from social media outlets including X (formerly known as Twitter), Facebook, and Instagram, among others. SML studies leverage the user-generated data to identify trends, behaviors, attitudes, and opinions on different topics (11, 12), and use a variety of methodologies for analysis such as content analysis, grounded theory, and computer-aided analysis methods like latent Dirichlet allocation, natural language processing, and sentiment analysis (11). In the context of healthcare, a social media listening study plays several essential roles: 1) Health Practice & Services: Social media listening studies often analyze user posts that relate to health practice, health services, and health education (11), 2) Adverse Event Detection: These studies can be helpful in detecting and monitoring adverse drug events reported by patients on SMPs (13), 3) Recruitment for Clinical Trials: Social media listening studies may also be used to

recruit participants for clinical trials. They can be particularly useful in attracting younger demographics without significant disparities in socio-economic variables or specific characteristics like smoking status (14). Regardless of the method used, SML studies contribute significantly to understanding public attitudes, monitoring trends and practices, and fostering research efforts in the healthcare field and these aspects would provide significant benefit for the understanding of the burden of urticaria in CU patients; however, the utilization of SML for these purposes in CU management is yet to be documented in the scientific literature.

The significant advantages that SML could offer in understanding a disease like CU would be obtaining patient insights on various aspects such as symptom progression, emotional distress, and quality of life disturbances. Healthcare practitioners could also gain insights into the patient's experience with medical treatments, including the effectiveness and side effects of various therapies as well as the roadblocks they encounter in patient journey which might not be always captured in clinical encounters. Thus, we aimed to conduct this study through SML to analyze how patients expressed their experiences with urticaria, in terms of symptoms, emotions and difficulties in diagnosis and management. Secondly, as it was shown that the COVID-19 pandemic had a marked impact on patient-physician interactions and reduced use of PROMs (15), we also aimed to investigate the effect of COVID-19 pandemic on CU patient experiences.

## **MATERIAL and METHODS**

### ***Data Collection, Segmentation and Qualitative Content Analysis***

A comprehensive search on SMPs was performed for Turkish language content posted between January 2018 and December 2022. In accordance with the aim of the study, keywords related to urticaria were defined for the analysis. All posts mentioning various combinations of these keywords (for example, 'urticaria', 'angioedema', and combination of the words wheal, itch, swelling, pruritus, allergy etc.) including all potential synonyms, written in a correct way or with linguistic mistakes, were included (supplementary Figure 1, 2).

Social Studio, a social media data aggregator tool, was used to capture relevant records. The content was manually curated to analyze and map psychological aspects with

descriptive statistics applied on aggregated findings. The content coming to the platform through keywords, phrases, and hashtags is analyzed using a partner research company.

X (Twitter), Instagram, Facebook, YouTube, and web channels (mainly mainstream blogs, dictionaries, forums, and news sites) were among the channels followed. Data was collected using web scraping methods. If the channels had their own application programming interfaces (API), these APIs were used. Only the content that was publicly visible was analyzed. Analysis details were within the scope allowed by the APIs of the relevant social media channels. To evaluate the effect of the COVID-19 pandemic on the analyzed contents, results were compared as pre-COVID-19 period (01.01.2018 - 31.12.2019) and COVID-19 period (01.01.2020 - 31.12.2022).

All data utilized and presented in this study were obtained from publicly accessible sources without accessing password-protected information. The privacy of the patients was respected and caution was taken in using the information posted by them: all online content was an-

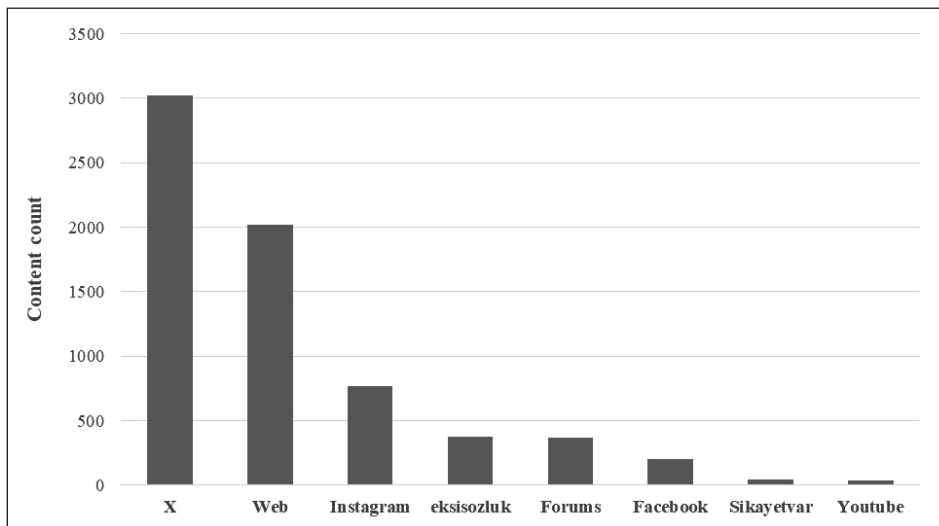
onymized, complying with the data privacy obligations. All data collected and analyzed will be kept for at least 15 years by the third party in concern. The study was approved by the institutional review board (Koç University: 2023.194.IRB3.090).

**RESULTS**

Keyword-based analysis of the SMPs determined for the study revealed a total of 34242 content, including 8763 content by 5238 unique users in the pre-COVID-19 period and 25479 content by 14546 unique users in the COVID-19 period. The most commonly searched categories in these content are shown in Table I.

In the pre-COVID-19 period, 46% of the identified users were female and most of them (31.8%) were aged between 25-29 years. The proportion of female users increased (58%) and the proportion of users over the age of 40 increased (50.4%) significantly in the COVID-19 period.

X (Twitter) was the most frequently used (44%) SMP for the entire study period (Figure 1). Some of the expres-



**Figure 1.** Most frequently used social media platforms for the entire study period.

**Table I: The five most commonly searched categories in all content.**

| Most searched categories           |                                  |                                    |
|------------------------------------|----------------------------------|------------------------------------|
| All content; n (%)                 | Pre-COVID-19; n (%)              | COVID-19; n (%)                    |
| Information: 11615 (34)            | Information: 2420 (28)           | Information: 9205 (36)             |
| Symptoms: 7075 (21)                | Emotions: 2196 (25)              | Symptoms: 4879 (19)                |
| Etiology: 6499 (19)                | Symptoms: 1620 (18)              | Etiology: 4633 (18)                |
| Emotions: 5805 (17)                | Etiology: 1172 (13)              | Emotions: 3665 (14)                |
| Diagnosis and treatment: 3697 (11) | Diagnosis and treatment: 778 (9) | Diagnosis and treatment: 3456 (14) |

sions used by patients about urticaria in their own words are exemplified in Table II.

***From the patients' perspective, the causes of urticaria are heterogenous and differ markedly between the before and during COVID-19 periods***

From the patients' perspective, the three most common causes of urticaria were chemical cleaners (4553 posts), stress/upset (2611 posts) and drug side effect/allergy (1467 posts) in the pre-COVID period, respectively. In the COVID-19 period, stress/upset (4809 posts), drug side effect/allergy (2302 posts), and having COVID-19 (1415 posts) were defined as the most common causes of urticaria. Both in the pre- and COVID-19 periods, patients were more likely to think that urticaria is a disease with seasonal variability (737 posts vs. 1644 posts, respectively). In the summer season, the number of urticaria-related posts increased by 15% compared to the winter season. In addition, the amount of posts in the summer season during COVID-19 increased by 247% compared to the amount

of mentions in the summer months before COVID-19. In the COVID-19 period, the causes of the disease have diversified considerably and causes such as histamine intolerance/allergy, rheumatic diseases, consumption of ready-to-eat foods, and collapse of the immune system have been increasingly posted, and the tendency to link different diseases with urticaria has increased.

***What CSU symptoms are most burdensome? What are the most frequently expressed emotions and feelings?***

Of all the posts discussing symptoms, "itching" was posted most frequently as the primary distressing symptom (14383 post, 42%), followed by "redness" (11348 post, 33%) and "swelling" (5314 post, 16%). Swelling in lips, eyes, tongue and/or throat were posted 2086 (6%) times. It was frequently reported that itching can occur on any part of the body, spread widely, flare up especially at night, and may cause sleep problems. Symptoms restrict patients from eating, drinking, dressing, and moving freely.

**Table II: Some of the most featured patient expressions about urticaria with the patients' own words (All content was translated from Turkish).**

|   |
|---|
| <i>Every month I live this stressful disease called urticaria again. I wake up with an extreme itch and my whole body is red. <b>Stress will kill me</b>, I can tell you that.</i>  |
| <i>It is the disease that ruined my vacation. I'm itching all over, red and blistering, some of them are big pieces, some of them are all over my body like mosquito bites. <b>Itching is digging me an early grave.</b></i>    |
| <i>Itching seems to go away during the day, but at night it itches to tear my hand.</i>   |
| <i>I'm convinced enough that <b>seeing different doctors has no help.</b></i>   |
| <i>I had managed with pills for 4-5 months. This time <b>if the urticaria doesn't kill me, the pills definitely will!</b></i>   |
| <i>For 10 years I have been suffering from chronic urticaria, but I can never get over it, I get vaccinated every 15 days, it only relieves me, but <b>it never ends.</b> How did you make it go?</i>                           |
| <i>Does this disease never go away? <b>Will I continue swelling until I die?</b></i>  |
| <i>Unfortunately, there is no medical treatment for chronic urticaria</i>   |
| <b><i>It is purely a psychological warfare</i></b>  |
| <i><b>You need to find the cause of the urticaria and confront it.</b> It could be anything. Whatever it is, find it and fight it!</i>  |
| <b><i>I tried to explain my problem to the doctor... I have swelling, redness and itching problems on my body.</i></b>  |
| <i>I rub my hands on the carpets, <b>I slap the walls</b>, I'm going crazy</i>  |
| <i>I was told it was urticaria and it could be caused by allergies, but <b>allergy tests were all clean.</b> I can't go a day without taking antihistamines. I'm going crazy</i>  |
| <i>The unpredictable attacks that <b>make one's life a nightmare...</b></i>   |
| <i>I'm tired of getting cortisone shots, I've lost my job because of this disease, find me a cure, <b>I'm dying slowly day by day.</b></i>  |
| <i>This is such a disgusting disease that ruins your life and it makes you hate yourself. I didn't want to see anyone for days, <b>my sexual life took a serious blow. Nothing I ate or drank gave me pleasure anymore.</b></i> |
| <i>Being subjected to statements such as "<b>do you have scabies</b>, you're puffed up like a balloon, you're like a beet"</i>  |
| <i>I saw my doctor and he said there was no cure for this disease and <b>I should get used to it.</b> He gave me allergy pills.</i>   |



Patients' most prominent feelings about the symptoms of urticaria were intense "pain" (696 posts), "getting bored" (497 posts), "embarrassment" (255 posts), and "helplessness" (187 posts). Patients describe the discomfort they feel due to the symptoms with very intense emotional expressions such as "being destroyed, losing a lifetime, going crazy". The recurrence of the disease, long disease duration, frequent visits to hospitals, and the ineffectiveness of medications caused patients to feel overwhelmed and bored.

### ***Challenges in the diagnosis of urticaria***

Challenges in the diagnostic process vary; the most frequently posted challenges include the multiple etiology of urticaria, the lack of definitive diagnostic methods, difficulty in reaching specialists, and the inconclusive results of allergy skin tests. Compared to the pre-COVID-19 period, the rate of these difficulties increased in the COVID-19 period (2% vs. 4.5%; 0.6% vs. 1.6%; 0.1% vs. 0.7%; and 1.2% vs. 4.5%, respectively).

### ***Challenges in the treatment of urticaria***

When we analyzed the posts in which the treatment drugs were clearly specified, 641 posts about corticosteroids, 277 posts about antihistamines, and 149 posts about omalizumab were identified. In addition to medications, alternative treatment methods such as cupping (n=127), herbal cure (n=71), hypnosis (n=35), and goat milk soaps (n=233) come to the forefront among the information searched for by the patients.

Patients mentioned that treatment of urticaria is a long and tiring process, that corticosteroids have many side effects, and that using regular medication is not a permanent solution. There were patients who reported miraculous results with some treatments and other patients reported relapsing after them. Among alternative treatment methods, it was stated that cupping and cold shock have relaxing effects; herbal cures, baby oil, and ozone therapy do not provide a definitive solution; and hypnosis is a definitive solution.

Patients believed that urticaria is closely related to stress and stated that they had difficulty coping with stress (pre-COVID: 1786 posts vs. COVID: 2655 posts related to stress). Apart from this, having to go to the hospital frequently to get injections/serums (2012 posts), frequent recurrence of the disease and the fact that it does not go away

for a long time (1719 posts) were frequently used topics that could be associated with treatment in the mentions.

Another difficulty experienced by the patients during the treatment process involves problems in the patient-doctor relationship. Patients primarily mentioned that they could not receive advice and support from physicians other than medication (232 posts).

### ***Patients seek to manage their urticaria in many different ways***

Patients often try to manage their urticaria by avoiding triggers, following dietary recommendations, and practicing methods to relieve symptoms. Avoiding stress, alcohol, certain medications and caffeine were posted 1648 times. In 883 posts, non-pharmaceutical product recommendations and/or natural product recommendations were made.

## **DISCUSSION**

Through social media listening analysis, we provided detailed information about patient experiences of urticaria and we were able to identify and analyze content related to urticaria on various SMPs including the impact of COVID-19 pandemic on social media behaviors of the patients. The analysis revealed the burden of disease with a different perspective than the PROMs, showing the heavy emotional impact of the disease on patients and how patients seek support on social media. Information, symptoms and emotions were the most frequently posted categories for both the pre-COVID and COVID periods.

Patients living with chronic conditions tend to interact with other patients having the same condition. They discuss their condition, share coping experiences, offer social support, and seek a way out from their disease, especially using social media. Other than patients, social media can be used by the public and health care professionals with the possibility of potentially improving health outcomes and for social mobilization (16). Our results demonstrated that X (Twitter) was the most frequently used SMP by urticaria patients. Nearly half of the posts were obtained from X. The evidence indicates that X serves as a potential platform for carrying out health campaigns (17). Thus, it might be advisable to enhance the dissemination of informative content regarding urticaria on this platform.

During the COVID-19 pandemic, there has been a noticeable increase in patient-generated content related

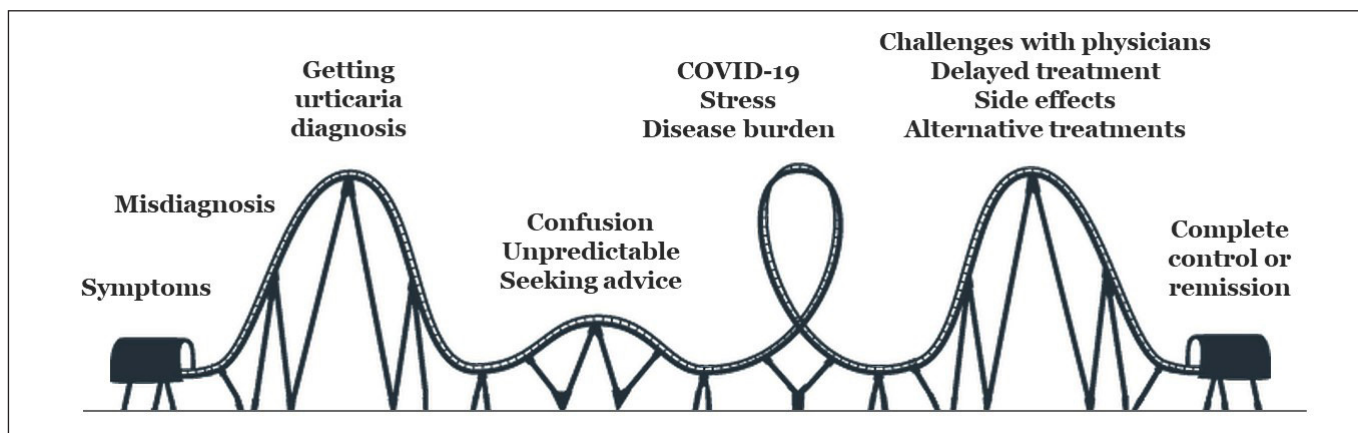
to urticaria on SMPs (18). This can be attributed to the negative impact on the quality of life caused by the pandemic, leading to higher levels of stress and social anxiety among individuals. This increase in stress and anxiety may exacerbate existing urticaria symptoms or trigger new episodes, prompting patients to seek support and share their experiences on social media. Through a social media-based investigation conducted in adult Chinese patients, it was observed that the outbreak of COVID-19 and the accompanying mental stress of income loss potentially contributed to increased urticaria activity (19). Furthermore, the increased use of social media during the pandemic allowed individuals to gather information and seek support regarding urticaria and its management. The use of social media platforms has provided a space for patients to connect with others facing similar challenges, share their experiences, and access information about urticaria and its connection to COVID-19 (20). Through the examination of content generated by patients on SMPs, we can acquire valuable insights into the real-life experiences of individuals dealing with urticaria amid the COVID-19 pandemic. This includes understanding their symptoms, treatment experiences, coping mechanisms, and any concerns or misconceptions they might have about the relationship between COVID-19 and urticaria.

SML analysis has revealed a shift in the discussion of urticaria during the COVID-19 pandemic. Before the pandemic, patients commonly discussed triggers such as chemical cleaners, stress/upset, and drug side effect/allergy. During the pandemic, there has been a significant increase in posts related to stress/upset and COVID-19 as a trigger for urticaria. It is evident that the global crisis has

not only affected the quantity of discussions but has also shaped the content and tone of conversations related to urticaria. Patients were concerned about the possible connection between their urticaria symptoms and COVID-19 infection (21). They are seeking information on whether urticaria can be a symptom or a manifestation of COVID-19. This information suggests that COVID-19 has had a noticeable impact on the discussion and perception of urticaria on social media platforms.

Our analysis provided valuable insights of individuals living with urticaria. Most prominent symptoms of the patients were itching, redness, and swelling. Besides their symptoms, patients also expressed that urticaria has an emotional and physical burden on their life. They expressed how they feel about their disease/condition using their own words like “nightmare, dying, warfare, never ending”. Humanistic and economic impacts of chronic spontaneous urticaria have been well shown before (4). Also, in accordance with our findings, Goldstein et al. have shown that patients with urticaria feel that their bodies are turning against them, using the term “skinemy” (22).

For patients with chronic urticaria, the journey from the first symptoms to diagnosis and to the suitable treatment is sometimes slow, exhausting, and challenging (Figure 2). Chronic urticaria is almost never a food or drug allergy as might be seen in acute urticaria (2). However, unnecessary allergy tests and negative results can be disappointing for patients. Patients mostly see more than one doctor before the diagnosis. It has been shown that the pathway of care was unsatisfactory in more than 80% of the patients and three physician consultations was needed before the di-



**Figure 2.** The journey of chronic urticaria from the first symptoms to spontaneous remission is sometimes slow, exhausting, and challenging for the patients and can be blocked or get out of the patients’ control by many different factors. .

agnosis or appropriate treatment in more than 75% (23). Likewise, the patients in our analyses posted the challenges they face in accessing appropriate medical care, including problems in patient-doctor relationship, lack of support, and the need for frequent hospital visits. Unfortunately, the difficulties and setbacks they face during the treatment push them to seek alternative solutions for symptom relief. Patients shared tips and remedies they had tried, such as natural remedies, diet modifications, and stress reduction techniques. They also posted that most of these alternative treatments do not provide a definitive solution. It is clear that patient-physician interaction in urticaria is limping and not satisfactory for the patients. To achieve better disease outcomes, patients need more support, and further education is needed for both the patients and physicians. The global network of Urticaria Centers of Reference and Excellence (UCAREs) consists of specialized referral centers for the management of urticaria, and aims to provide excellent patient care and CU management, increase the knowledge of urticaria, and promote the awareness of urticaria (24). The specialized centers aim to improve the time and care provided for each chronic urticaria patient and ensure detailed answers are given to each patient to satisfy their questions about the disease. The network also aims to provide up-to-date information by the experts in the field to increase knowledge about urticaria for both the physicians and patients. The UCARE network has the potential to bridge gaps in patient-physician interaction and alleviate challenges encountered by individuals with urticaria throughout their journey with the condition.

Our study's strengths lie in its extended duration, allowing for a comprehensive analysis and comparison of trends before and after the COVID-19 pandemic. For the limitations, it was not possible to exactly differentiate acute and chronic urticaria, and different phenotypes and subtypes of CU such as inducible or spontaneous. Secondly, findings in this social media listening analysis were retrospectively analyzed without a hypothesis to be tested.

In summary, the influence of COVID-19 on the discussions surrounding urticaria on social media platforms has been significant. The analysis revealed how the pandemic has influenced access to care and how stress and the COVID-19 became the leading triggering factors for urticaria. On the other hand, our study revealed the high emotional impact of the disease on the patients. These findings can be instrumental in understanding the evolving landscape of urticaria awareness and navigating the challenges. Un-

derstanding these challenges is crucial for healthcare professionals and organizations aiming to effectively address and support individuals with urticaria. Continued exploration and examination of social media listening concerning health issues, including urticaria across diverse global regions, will be essential to remain informed about the evolving landscape of public discussions and perceptions.

#### Conflict of Interest

**Murat Turk** has no relevant conflict of interest in relation to this work. Outside of it, **Murat Turk** is or recently was a speaker and/or advisor for AstraZeneca, Chiesi, GSK, Novartis, ROXALL, Vem İlaç.

**Bora Baysal** is an employee of Novartis.

**Ragip Ertas** is or recently was a speaker and/or advisor for Novartis, Abbvie, Janssen, and Pfizer.

**Andac Salman** has no conflicts of interest in relation to this work. Outside of it, he is or recently was a speaker and/or advisor for Abbvie, Amgen, Bayer, Menarini, Novartis, Pfizer, and Sanofi.

**Emek Kocaturk** is or recently was a speaker and advisor for Novartis, Menarini, LaRoche Posey, Sanofi, Bayer, Abdi İbrahim, Pfizer.

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#### Authorship Contributions

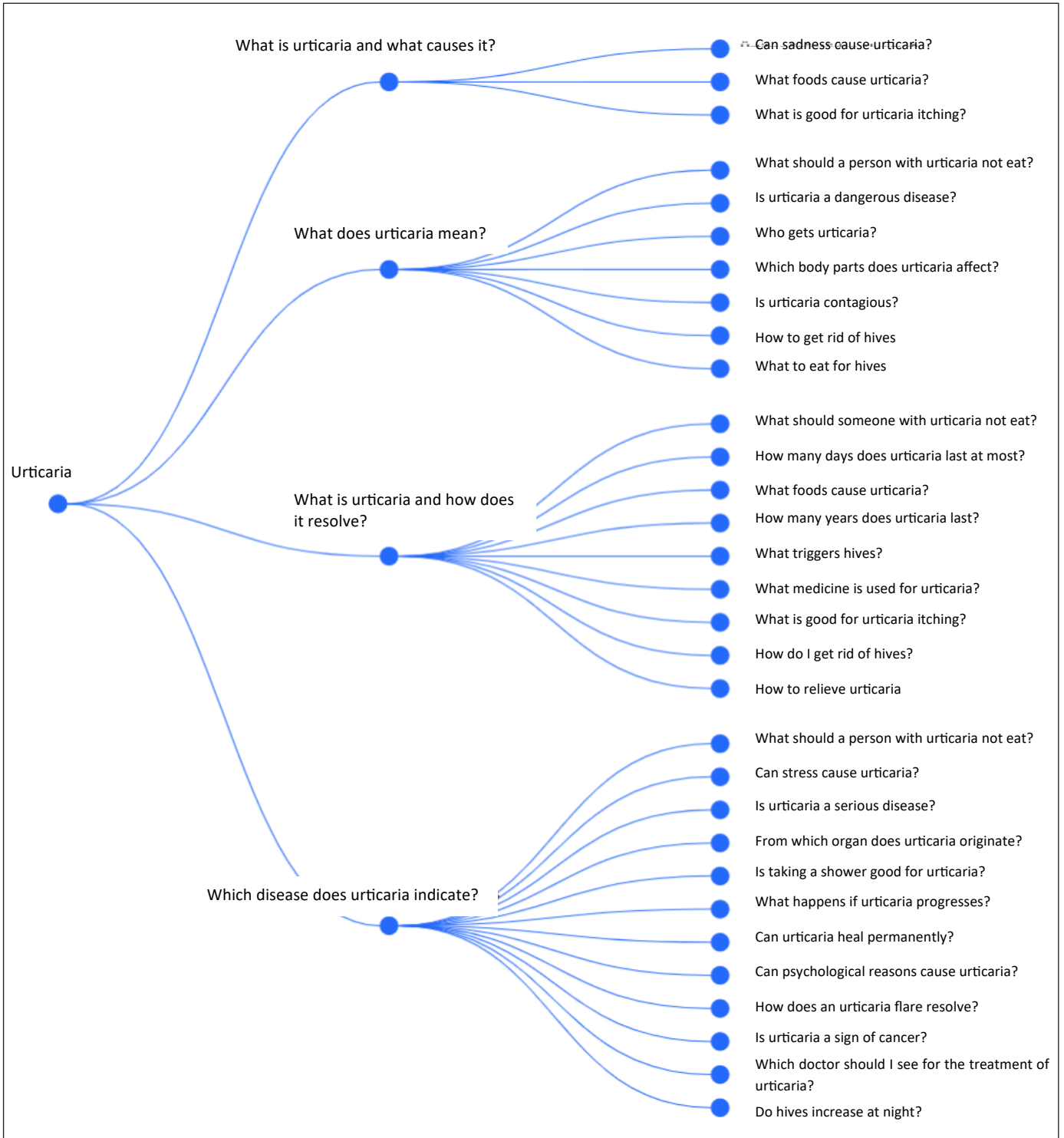
Concept: **Murat Turk, Bora Baysal, Ragip Ertas, Andac Salman, Emek Kocaturk**, Design: **Murat Turk, Bora Baysal, Ragip Ertas, Andac Salman, Emek Kocaturk**, Data collection or processing: **Murat Turk, Bora Baysal, Ragip Ertas, Andac Salman, Emek Kocaturk**, Analysis or Interpretation: **Murat Turk, Ragip Ertas, Andac Salman, Emek Kocaturk**, Literature search: **Murat Turk, Ragip Ertas, Andac Salman, Emek Kocaturk**, Writing: **Murat Turk, Ragip Ertas, Andac Salman, Emek Kocaturk**, Approval: **Murat Turk, Bora Baysal, Ragip Ertas, Andac Salman, Emek Kocaturk**.

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**Supplementary Figure 1.** Most frequently asked questions about urticaria found in the web.



Supplementary Figure 2. Most frequently asked questions about hives found in the web.