

Insight into the patient experience of eczema through a crowdsourcing approach



Annie R. Wang, MD, Abrar A. Qureshi, MD, and Aaron M. Drucker, MD

Clinical Implications

- We examined posts related to eczema on social media as an unsolicited crowdsourcing approach to investigating burden of disease.
- Anticipatory anxiety related to eczema flares is a potential area of patient concern identified in this study.

TO THE EDITOR:

Health care professional (HCP) and researcher assessment of the severity of eczema (also called atopic eczema or atopic dermatitis) and its impact on quality of life is often poorly correlated with patient-reported outcomes.¹⁻³ With the increased use of social media to share and discuss medical conditions, crowdsourcing is a potential means to better understand the patient disease experience.⁴ We conducted a study to determine the feasibility of using social media to study the patient perspective of living with eczema. This study was approved by the Brown University Institutional Review Board.

Using the software platform of a social media monitoring company (Brandwatch, Brighton, UK), a comprehensive query was designed to search all English mentions of eczema (search terms included eczema OR excema OR exzema OR exema OR atopic dermatitis) in January and July 2015 in the United States. These months were selected to represent winter and summer, respectively. Social media sites included Twitter (San Francisco, Calif), where users share 140-character messages known as “tweets,” and Facebook (Menlo Park, Calif), where users link their account to known “friends” and share links and messages, Tumblr (New York City, NY), a microblog networking service that allows users to post multimedia and blogs, and Instagram (San Francisco, Calif), a mobile photo/video-sharing service.

The software attempted to categorize posts originating from “patients” (terms used: “I” or “me” or “I have” or “I have been suffering”), friends/relatives (“mom,” “dad,” “son,” “cousin,” “daughter”), or HCPs (“I recommend”). These posts were then manually screened for authenticity to exclude advertisements or posts from fake accounts that the software could not exclude on its own. Word clouds based on a random sample of 600 mentions identified phrases commonly associated with eczema in social media posts. In these word clouds, font size increases proportionally to the number of times the phrase is used (ie, larger font represents increased number of mentions).

In total, 79,029 posts from January (57%; 45,613 posts) and July (43%; 33,669 posts) were identified by the software as being related to eczema. In January, posts were from Twitter (66%; 30,282), Facebook (25%; 11,192), blogs (3%; 1,447), forums (2%; 1,017), news (2%; 783), and unspecified Web sites

(1%; 655). In July, posts were from Twitter (83%; 27,985), blogs (6%; 1,890), Facebook (3%; 1,073), forums (3%; 999), news sources (3%; 1,000), and other unspecified Web sites (2%; 514). Word clouds (Figure 1) identified phrases associated with skin signs (eg, “skin discoloration”) and treatment options (ie, “skin care,” “cream,” “lotion”). Some phrases (eg, “Mom To Let Him Die”) were later eliminated when screening for advertisements.

After software screening for patient, friends/relatives, or HCP-related posts, a total of 6371 posts (8% of total) were identified; 3656 (57%) from January and 2715 (43%) from July. Of these, most posts were from Twitter (76% in January, 81% in July), followed by Facebook (13%, 7%), blogs (5%, 4%), and forums (3%, 5%).

A manual review of software-screened posts confirmed that 2513 of 3633 (69.5%) posts in January and 1925 of 2696 (71.4%) posts in July were authored by patients, representing 6% of all eczema-related posts. Word clouds generated from these manually verified patient-only posts are presented in Figure 2. The most common phrases associated with eczema in January (Figure 2, A) included “hate having eczema” (n = 127), “dry skin” (n = 72), “suffering from eczema” (n = 66), “eczema is so bad” (n = 60), and “eczema is coming” (n = 48). All 48 posts with the phrase “eczema is coming” were used in the context of “eczema is coming back.” In July (Figure 2, B), common phrases associated with eczema included “hate having eczema” (n = 225), “living with eczema” (n = 53), “hate my eczema” (n = 53), and “eczema on my hands” (n = 31). The software identified 12 posts authored by HCPs; 11 were advertisements. Twenty-seven posts authored by friends/relatives were manually verified to be authentic.

In this study, we found that many people in the United States use social media to discuss eczema, with 4438 posts identified over 2 months in 2015. Much of the sentiment in these posts was negative, with commonly occurring phrases such as “hate having eczema” and “suffering from eczema” appearing prominently in the word clouds. An interesting theme that emerged from patient-authored posts is the element of anxiety in anticipation of flares, reflected by the phrase “eczema is coming.” Anticipatory anxiety, the concept of apprehension toward a situation or stimulus that can cause significant anxiety before experiencing the actual situation or stimulus, is a feature of many anxiety disorders and phobias.⁵ Eczema has been associated with increased rates of anxious symptomatology and anxiety disorders,⁶⁻⁸ and it is possible that some of this may be related to its relapsing course and anticipatory anxiety. Further research characterizing and quantifying anticipatory anxiety in eczema would be valuable.

We acknowledge a number of limitations. The diagnosis of eczema is self-reported among those posting. Furthermore, we examined posts only from 2 sample months. Evaluating trends over an entire year or years may improve the utility of social media for patient-oriented research. Posts included in this study were all publicly viewable and largely from Twitter due to increased privacy settings on other sites. Factors such as personality, willingness to share, and technological adeptness may play a role in people who post on social media about their



FIGURE 1. Word clouds associated with eczema from posts in January (A) and July (B) 2015 before software or manual screening for authorship by patient, relative, or HCP.



FIGURE 2. Word clouds generated from patient-authored posts only (as identified by the social media monitoring software and after manual verification) from posts in January (A) and July (B) 2015.

medical conditions compared with the general population. The large volume of advertisements, including automated retweets by software applications (eg, “bots”), is difficult to differentiate from authentic posts both by software and by manual screening. Fewer than 75% of posts identified by the software as being authored by patients were confirmed by our manual review, demonstrating the current limitations of relying on software only for this research. There were also very few posts by HCPs identified in our study. Although this may be due to limitations in the software platform, previous studies also noted a lack of reputable dermatology presence on social media.⁹

The major strength of our study is its use of an unsolicited crowdsourcing approach where people posted about eczema of their own accord, unprompted by specific questions from clinicians or researchers. Social media has the potential to yield genuine and illustrative insight into the experience of living with eczema compared with other methods of patient-oriented research such as qualitative interviews, focus groups, or surveys. Therefore, despite its limitations, unsolicited crowdsourcing via social media can be a useful research technique.

Acknowledgments

We thank staff at Brandwatch (Brighton, UK) for their help on this project.

Department of Dermatology, Alpert Medical School of Brown University, Providence, RI

This study was funded in part by the National Eczema Association.

Conflicts of interest: A. R. Wang has received research support from the National Eczema Association. A. A. Qureshi has received research support from the National Eczema Association; has received honoraria that have been donated to charity from AbbVie, Amgen (investigator), the Centers for Disease Control and Prevention, Janssen, Merck, Pfizer (consultant), and Novartis; and is an investigator for Amgen, Regeneron (no financial compensation), and Sanofi (no financial compensation). A. M. Drucker has received research support from the National Eczema Association, Regeneron (no financial compensation), and Sanofi (no financial compensation) and has received an honorarium (speaker) from Astellas Canada.

Received for publication September 13, 2016; revised October 14, 2016; accepted for publication October 21, 2016.

Available online November 30, 2016.

Corresponding author: Aaron M. Drucker, MD, Department of Dermatology, Brown University, Box G-D, Providence, RI 02912. E-mail: Aaron_Drucker@brown.edu. 2213-2198

© 2016 American Academy of Allergy, Asthma & Immunology
<http://dx.doi.org/10.1016/j.jaip.2016.10.016>

REFERENCES

1. van Valburg RW, Willemsen MG, Dirven-Meijer PC, Oranje AP, van der Wouden JC, Moed H. Quality of life measurement and its relationship to disease severity in children with atopic dermatitis in general practice. *Acta Derm Venereol* 2011;91:147-51.
2. Zhao CY, Tran AQ, Lazo-Dizon JP, Kim J, Daniel BS, Venugopal SS, et al. A pilot comparison study of four clinician-rated atopic dermatitis severity scales. *Br J Dermatol* 2015;173:488-97.
3. Capozza K, Shao Y, Zeng QT. "Crowdsourcing": a patient-centered research agenda for pediatric atopic dermatitis. *Int J Dermatol* 2016;55:1414-6.
4. Armstrong AW, Harskamp CT, Cheeney S, Schupp CW. Crowdsourcing in eczema research: a novel method of data collection. *J Drugs Dermatol* 2012;11:1153-5.
5. American Psychiatric Association. Anxiety disorders. In: *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*. Washington, DC; 2013. Available from: <http://dsm.psychiatryonline.org/doi/10.1176/appi.books.9780890425596.dsm05>. Accessed February 8, 2016.
6. Simpson EL, Bieber T, Eckert L, Wu R, Ardeleanu M, Graham NM, et al. Patient burden of moderate to severe atopic dermatitis (AD): insights from a phase 2b clinical trial of dupilumab in adults. *J Am Acad Dermatol* 2016;74:491-8.
7. Dalgard FJ, Gieler U, Tomas-Aragones L, Lien L, Poot F, Jemec GB, et al. The psychological burden of skin diseases: a cross-sectional multicenter study among dermatological outpatients in 13 European countries. *J Invest Dermatol* 2015;135:984-91.
8. Slattery M, Essex MJ, Paletz EM, Vanness ER, Infante M, Rogers GM, et al. Depression, anxiety and dermatologic quality of life in adolescents with atopic dermatitis. *J Allergy Clin Immunol* 2011;128:668-71.
9. Amir M, Sampson BP, Endly D, Tami JM, Henley J, Brewer AC, et al. Social networking site: emerging and essential tools for communication in dermatology. *JAMA Dermatol* 2014;150:56-60.

Reproduced with permission of copyright owner.
Further reproduction prohibited without
permission.