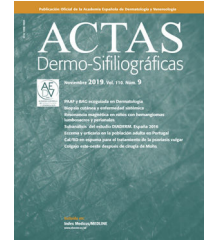




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ORIGINAL ARTICLE

Social Networks and Atopic Dermatitis: Cross-Sectional Descriptive Study[☆]



Á. Iglesias-Puzas,^{a,*} A. Conde-Taboada,^a L. Campos-Muñoz,^a I. Belinchón-Romero,^b E. López-Bran^a

^a Servicio de Dermatología, Hospital Universitario Clínico San Carlos, Madrid, Spain

^b Servicio de Dermatología, Hospital General Universitario de Alicante, ISABIAL-UMH, Spain

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KEYWORDS

Atopic dermatitis;
Social media;
Facebook;
Twitter;
LinkedIn.

Abstract

Background: Social networks have become key tools for finding and disseminating medical information.

Objective: To describe the characteristics of social network postings on atopic dermatitis, the content that is posted, and the number of followers of pages, groups, or accounts.

Materials and methods: We selected pages, groups, or accounts related to atopic dermatitis on Facebook, Twitter, and LinkedIn and followed them in January and February 2020. For each site, group, or account we recorded country of origin, year created, purpose, presence of links, provision of a contact email, and number of followers. We also analyzed the topics treated in recent content posts on the pages with the largest numbers of followers in each network.

Results: A total of 257 pages, groups, or accounts were included: Facebook, 171; Twitter, 59; and LinkedIn, 27. Facebook had the largest total number of pages and mean (SD) number of followers: 1416.71 (3722.63). Patient support groups accounted for most of the pages (63%), but businesses or product offers had more followers ($P < .035$). Of the 909 posts of informative content we analyzed, the most frequent topic was “general information about atopic dermatitis” (27.94%).

Conclusion: Our findings show the importance of clearly defining the roles and limitations of social media platforms for designing future information campaigns and new patient-centered approaches to reaching patients with atopic dermatitis.

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* Corresponding author.

E-mail address: alvaroigpu@gmail.com (Á. Iglesias-Puzas).

PALABRAS CLAVE

Dermatitis atópica;
Redes sociales;
Facebook;
Twitter;
LinkedIn

Redes sociales y dermatitis atópica: estudio descriptivo transversal**Resumen**

Antecedentes: Las redes sociales se han convertido en una herramienta clave para la búsqueda y difusión de información médica.

Objetivo: Describir las características de las páginas relacionadas con la dermatitis atópica en las redes sociales, la temática de sus publicaciones y el grado de seguimiento que se realiza de ellas.

Material y métodos: Se seleccionaron páginas, grupos o cuentas relacionadas con la dermatitis atópica en Facebook, Twitter y LinkedIn durante los meses de enero y febrero de 2020. De cada una de ellas se recogieron: el país de origen, año de creación, objetivo, presencia de enlaces a páginas web, existencia de correo electrónico y número de seguidores. Además, se realizó un análisis de las temáticas más frecuentes en las últimas publicaciones de las páginas con más seguidores de cada red social.

Resultados: Se incluyeron en el estudio un total de 257 páginas, grupos o cuentas (171 en Facebook, 59 en Twitter y 27 en LinkedIn). Facebook obtuvo un mayor número medio (\pm DT) y total de seguidores ($1416,71 \pm 3722,63$). Los grupos de apoyo a pacientes fueron el tipo de página más frecuente (63%), aunque aquellas clasificadas como empresas o venta de productos obtuvieron un mayor número de seguidores ($p < 0,035$). Se analizaron 909 publicaciones, siendo "Información general sobre dermatitis atópica" la temática más frecuente (27,94% del total). *Conclusiones:* Nuestros hallazgos ponen de manifiesto la importancia de definir claramente el papel y las limitaciones de estas plataformas para orientar futuras campañas de información y desarrollar nuevos modelos centrados en el paciente con dermatitis atópica.

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Introduction

Atopic dermatitis (AD) is a chronic inflammatory disease with a prevalence of up to 20% in developed countries.¹ It is characterized by pruritus and recurrent eczema lesions that are associated with major morbidity and deterioration of patient quality of life, similar to that of other chronic diseases such as diabetes, epilepsy, and cystic fibrosis.²

In the age of technology, new advances have not only revolutionized the treatment of AD but have also transformed the way in which our patients and their caregivers obtain information on the disease.³ In recent years, social media have become a key tool for disseminating health-related news and promoting the exchange of medical information. Platforms such as Facebook, Twitter, and LinkedIn have millions of microblogs that act as online communities, dealing with topics from health promotion to the treatment or education of patients with AD.⁴ These forums are increasingly popular and have become an additional source of evidence, therapy, or support for our patients.⁵

Studies suggest that these channels may serve to communicate messages in an efficient, functional, and transparent way to a mass audience.⁶ However, the presence and following of these online platforms on AD, and the topics of their posts are unknown. The objective of this study is to describe the characteristics of pages related to atopic dermatitis on social media, the topics of their posts, and the extent to which they are followed in order to identify failings and guide future information campaigns.

Materials and Methods

The methods used are similar to those described by Meng et al. in the field of epilepsy and social media.⁷ The social media selected were Facebook, Twitter, and LinkedIn; Instagram was excluded due to the limitation of its search engine to providing a maximum of 55 results (even when more exist) in most cases. A search was performed on the included platforms during the months of February and March 2020, using the terms "dermatitis", "atopic", "eczema", and "atopy", separately and in combination. Two dermatologists with experience in atopic dermatitis (A.I.P. and A.C.T.) selected the pages, accounts, or groups on social media with a theme related to atopic dermatitis, based on the title, summary, or additional information in each case. Pages in languages other than English or Spanish and pages not exclusively related to the disease or not centered on humans were excluded.

The country of origin, year created, presence of links to informative websites, existence of a contact e-mail address, and total number of followers were recorded for each record included. For Facebook, the total number of followers was considered to be equivalent to the number of likes of the page or group. Each page, group, or account was then classified according to its purpose, based on the title, page description, and related activity. To perform this classification, following an exploratory analysis of the first 90 records included in the study (45 from Facebook, 30 from Twitter, and 15 from LinkedIn), the following categories were designated "Patient support groups", "Research and new therapies", "Companies or

product sales”, and “Personal/individual experiences or opinions”.

In the second phase of the study, the topics of the last 20 posts of the 20 records with the most followers/likes from each social media platform were analyzed to determine how many of them provided general information on the disease, information on care or treatment of the skin, support or answers to queries, promotion or sale of products, received thanks from patients, or none of the foregoing. In cases in which the total number of posts was less than 20, we collected only those that were available. All the data were analyzed independently by 2 dermatologists and disagreements between them were evaluated by a third researcher (L.C.M.).

Statistical Analysis

The data were analyzed using version 26 of the SPSS statistical software package. Frequency distribution was calculated for qualitative variables and mean and median, and standard deviation for quantitative variables. When non-normal distribution of the data was confirmed by means of the Kolmogorov-Smirnov test, nonparametric tests were used to evaluate the differences between the mean number of users of each social network platform. Values of $P < .05$ were considered to be statistically significant for all analyses.

Ethical Considerations

The study did not require the approval of the hospital’s ethics and clinical research committee, as it did not include direct evaluation or collection of identifiable patient data. All the data were obtained from sources considered to be public-access, the page names were omitted, and no interaction of any kind was held with the users of the social media platforms.

Results

A total of 257 pages, groups, or accounts from the 3 social media platforms were included in the study (171 on Facebook, 59 on Twitter, and 27 on LinkedIn). Facebook was the platform with the greatest total and mean number of followers per record (total, 251218; mean, 1460.57), with significant differences between the number of followers on the social media platforms studied ($P < .001$ Kruskal Wallis). In cases where the origin was reported (149), the Americas was the most frequent, accounting for 19.8% of cases. Links to websites were present in 42.8% of records, whereas only 9.3% provided a contact e-mail address. The pages, groups, or accounts with links to websites presented a higher mean number of followers (1605.89; $P < .001$ Mann Whitney U).

The most frequent objective of each page, group, or account on Facebook and LinkedIn was that of “Patient support groups” (72.4% and 52.9%, respectively), whereas on Twitter, the most frequently observed objective was expressing “personal/individual experiences or opinions”, accounting for 42.4% of cases. Table 1 shows the distribution of each category in the 3 social media platforms. Significant differences were observed between the number of

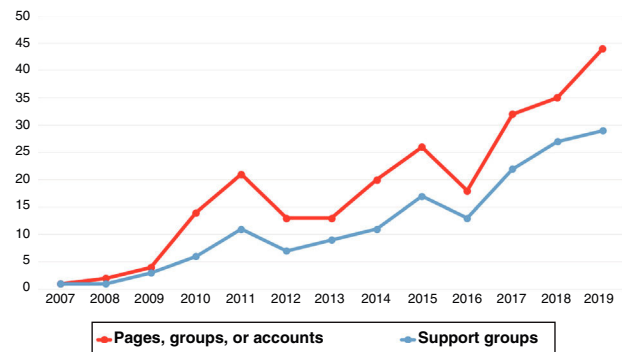


Fig. 1 Trend over time of the number of pages, groups, or accounts in general and for support groups in particular.

followers and the purpose of the page, group, or account ($P = .035$ Kruskal Wallis); records classified as “companies or product sales” presented a higher number of followers (1616.14 [3162.5]).

Fig. 1 shows the evolution over time of the pages, groups, or accounts on the 3 social media platforms studied. The figure shows the number of records created each year in total and with respect only to “Patient support groups” in particular. A total of 14 records did not mention the year in which activity began on the platform and were therefore excluded from this analysis.

In the second part of the study, the topics of the last 20 posts of the 20 pages, groups, or accounts with the most followers on each social media platform were analyzed. A total of 909 posts were included (395 from Facebook, 297 from Twitter, and 117 from LinkedIn). “General information on atopic dermatitis” was the most frequent topic, accounting for 27.94% of posts. Most of these posts provided open data on the pathogenesis or nature of the disease; e.g., “Atopic dermatitis is estimated to affect between 10% and 20% of children and between 1% and 3% of adults” or “Atopic dermatitis tends to appear in babies at the age of 5 months...”. The second most frequent topic was “support or answering queries”, accounting for 23.65% of the total. These posts or tweets focused predominantly on answering questions related to treatment or triggers of the disease; e.g., My doctor has recommended this product. *Has anyone used it?*, *What is your opinion on bleach baths?*, *Can atopic dermatitis get worse at the start of winter?* Other topics shown in our analysis included “information on the care or treatment of the skin” (e.g., *guide to determining what type of excipient we need based on the location of the lesions*), “promotion or sale of products” (e.g., *Dermatologists recommend it, get rid of dermatitis with this product*) and “thanks”. Fig. 2 shows the main topics observed and their frequency after analyzing 909 posts.

Discussion

Social media are an increasingly widely used resource for exchanging and accessing dermatologic content. Thanks to their capacity for direct communication in real time and to the ability to create virtual communities, social media have become a powerful tool for medical research.^{8,9} Particularly in chronic diseases, such as AD, the flexible format

Table 1 Main Characteristics of the Pages, Groups, or Accounts on the 3 Social Media Platforms Studied.

		[0.3-5]Social Media Platform			Total
		Facebook	Twitter	LinkedIn	
Pages, groups, or accounts		171 (66.5)	59 (23)	27 (10.5)	257
Number of followers	Total	242258	74570	2894	319722
	Mean (SD)	1416.71 (3722.63)	1263.89 (1915.5)	107.19 (195.05)	1244 (3192)
Continent	Total	116 (67.8)	23 (39)	10 (37)	149 (58)
	Americas	33 (19.3)	10 (16.9)	8 (29.6)	51 (19.8)
	Europe	11 (6.4)	25 (42.4)	6 (22.2)	42 (16.3)
	Asia	6 (3.5)	1 (1.7)	3 (11.1)	10 (3.9)
	Oceania	1 (0.6)	0	0	1 (0.4)
	Africa	4 (2.3)	0	0	4 (1.6)
Links	Yes	45 (26.3)	43 (72.9)	22 (81.5)	110 (42.8)
	No	126 (73.7)	16 (27.1)	5 (18.5)	147 (57.2)
E-mail	Yes	24 (14)	0	0	24 (9.3)
	No	147 (86)	59 (100)	27 (100)	233 (90.7)
Purpose	Support groups	127 (74.3)	21 (35.6)	14 (51.9)	162 (63)
	Research and new therapies	16 (9.4)	3 (5.1)	3 (11.1)	22 (8.6)
	Companies and product sales	10 (5.8)	10 (16.9)	8 (29.6)	28 (10.9)
	Personal opinions	18 (10.5)	25 (42.4)	2 (7.4)	45 (17.5)

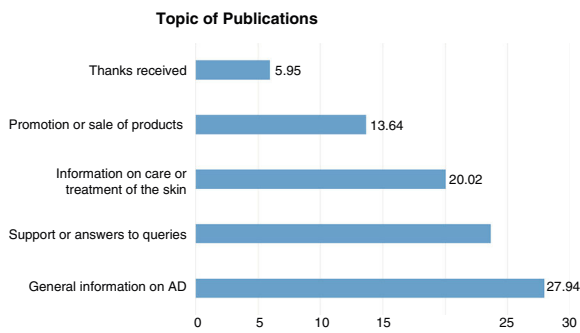


Fig. 2 Topics most frequently observed in the analysis of 909 posts on Facebook, Twitter, and LinkedIn.

of these platforms, without filters, and widely accessible, provides an innovative approach to identifying needs that are not covered in patient care.⁹ Furthermore, communicating in forums and online messages may facilitate scientific discourse and become established as a valid alternative for planning behavioral or prevention interventions based on the experiences and opinions of populations.

Our results show not only that patients with AD are avid users of social media (319,722 users/likes in total) but also that the presence and following of this entity is different in the social media platforms studied. Overall, Facebook appears to have greater potential than Twitter and LinkedIn in terms of the reach of its posts on AD, with a significantly greater mean number of followers per record (1460.57, $P < .001$ Kruskal Wallis) (Table 1).

Previous studies in the field of dermatology suggest that information on social media “probably or very probably” influences future decisions made by the patient regarding their medical care.¹⁰ Patients’ access to information allows for active participation in their care, turning them into true consumers of knowledge about their disease.^{11,12} It is notable that, although patient-centered organizations obtained better representation in terms of number of pages (63% of the total), records classified as “companies or product sales” had the greatest mean number of followers ($P < .035$) (Table 1). The reach of social media means that these commercial organizations can advertise or facilitate the purchase of products related to AD for a mass audience. This is a matter that generates debate due to the free, unlimited and often uncontrolled ability to upload content to social media. It is on this point that dermatologists and different organizations have expressed concern and the need for measures to ensure the veracity and quality of the information made available to users.^{8,13}

On the other hand, research on AD was the least frequent purpose on the social media platforms studied (22 records, 8.6% of the total). This is in contrast with the high frequency reported for the use of social media in research with dermatologic patients.¹⁴ In 2017, Howells et al. used social media to select individuals with AD and understand their experiences in relation to the long-term control of eczema. Through 6 online groups, the patients and their caregivers were able to provide their view of this concept in an effective and accessible manner.¹⁵ The incorporation of these online communities into experimental research may facilitate patient recruitment via the rapid dissemination

of online surveys, thereby identifying potential research subjects.¹⁴

Social media are a growing resource for influencing behavior, decisions, and perceptions relating to health.¹⁶ Our study has shown an increase over time in the number of pages, groups, or accounts related to AD, probably due to an increase in support groups (Fig. 1). Patients are increasingly active online and use social media to participate, share their concerns, and express themselves freely regarding their disease. The results of this study suggest that patients with AD, as well as actively sharing their experience on social media, receive a large amount of information from other users, patients, or organizations through their posts. A total of 71.61% of the posts analyzed provide “information on AD”, “information on skin care”, or “answers queries or provides support”. These results highlight the ability of users to disseminate materials and opinions related to AD, or even to educate a wide audience on skin care through their posts.

Our study provides a general updated view of the situation of AD on social media. However, it may be limited by the inability to include all social media platforms or by not having used all the search key words on the topic. Other biases inherent to any analysis of social media content, such as the publication bias of the experiences and opinions of users that were not published in any of the 3 platforms may also limit the conclusions of this study. Moreover, the changing nature of some of the variables used, such as the number of followers or the topics of the posts on each page should be taken into account.¹⁷

Conclusion

Listening to social media provides us with an opportunity to consider behaviors and interactions that are difficult to evaluate using traditional research methods.^{9,18} Our study illustrates the current situation and the evolution over time of AD on 3 of the main social media platforms. Of particular interest are findings such as the mass following of companies and pages related to product sales in AD, the exponential growth in recent years of patient support groups, and the high potential of users for disseminating materials and opinions relating to AD through their posts. All these data highlight the importance of clearly defining the role and limitations of these platforms for orienting future information campaigns and developing new models centered on patients with AD.

Conflicts of Interest

The authors declare that they have no conflicts of interest.

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