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#### ORIGINAL ARTICLE



# Patients' testimonies, feelings, complaints and emotional experiences with dermatoses on open social media: The French infodemiologic patient's free speech study

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#### Abstract

**Background:** Dermatoses represent a significant burden. Patients and their caregivers can turn to social media and digital communities to exchange with each other. These public exchanges constitute real-life data that can be analysed to better understand the patients' feelings and expectations, and the daily difficulties encountered. **Objective:** An infodemiologic study of public testimonies of patients and caregivers related to five dermatoses: eczema, rosacea, vitiligo, acne and psoriasis, over a 3-year time frame (September 2018 to September 2021) in France. To identify main topics of discussion, encountered difficulties and unmet medical needs.

**Methods:** Data extraction was performed based on a list of pertinent keywords. Webusers' profiles were determined by a specifically trained machine learning algorithm. Encountered difficulties were identified by manual annotation based on a standardized search grid. Co-occurrence analysis of difficulties allowed contextualization of challenges and unmet needs for each dermatosis.

**Results:** A total of 20,282 messages coming from 16,800 web users was extracted. The main topics of discussion were 'Impact on self- image and self-confidence' (23.6%), 'Generic discussion about therapeutics' (23.3%) and 'Burden of others' gaze' (12.8%). The top three mentioned difficulties for the five targeted dermatoses were similar and focused on 'Fear of/and management of symptoms', 'Impact on/and mood management' and 'Damaged self-image'.

**Conclusion:** This infodemiologic study highlighted the real-life management of five skin diseases by patients and their caregivers, who turned to social networks to openly express their suffering and seek solutions. The joined analysis of the five diseases enabled a common comprehension of what it is to live with a skin disease, from a patient-centric point of view. The specific analysis of each patient group objectified specific challenges, and main unmet medical needs.

# INTRODUCTION

Skin diseases are among the most common health problems worldwide and are associated with a considerable burden.<sup>1</sup> Despite the high prevalence of chronic skin conditions,<sup>2,3</sup> there is a lack of recognition on how patients suffer from the psychological burden of dermatoses.<sup>4</sup> Beyond the neuropsychological comorbidities of skin disease, it also affects patients' and their families' quality of life (QoL), socially, and financially.<sup>1</sup> Psoriasis prevalence

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in Europe has been estimated at 5% and at 5.5% for atopic dermatitis (AD).<sup>5</sup> The relationship between psoriasis and psychosocial stress is complex with a potential vicious circle where they are self-perpetuating.<sup>6-8</sup> A study revealed that the impacted self-image mainly due to embarrassment by their appearance led to a feeling of anger among AD patients.<sup>9</sup> Among the paediatric population with eczema, behavioural problems were identified, such as increased dependency on others, fearfulness and sleep difficulties.<sup>10</sup> Vitiligo affects approximately 1% of the global population and is identified to be a greater issue for patients with pigmented skin and to be the cause of greater disability.<sup>11,12</sup> About 75% of vitiligo sufferers find their appearance moderately to severely intolerable.<sup>13</sup> Rosacea is a common and chronic skin disorder, whose prevalence ranges from 0.1% to 22%.<sup>14-17</sup> The management of patients with a skin disease would benefit from a better recognition and care of the psychological burden associated with their skin disease. Assessing the burden of skin diseases is recognized to be crucial for allocating resources and positioning dermatologic care in a global health perspective; yet, the choice of the appropriate method remains a challenge.<sup>4,18</sup> Social media is a place where patients who are willing to express themselves can connect and exchange, looking for support and information. Infodemiology, as the exploitation of such data, allows a new perspective on psychosocial analysis of the specific population of patients expressing themselves on social media about their disease.

### **METHODS**

### Study design and population

This non interventional, retrospective, patient-centric, mixed-method study included data gathered from open social media posts (e.g. Twitter, Youtube, web forum or blogs such as Doctissimo, AuFéminin JournalDesFemmes, Carenity), written in French by patients affected by one of five dermatoses: rosacea, eczema, vitiligo, acne, psoriasis and their caregivers. Publicly available messages, posted between September 2018 and September 2021, were considered. Private account posts or data restricted posts were not included in the data set.

#### **Data extraction**

In this study, we constructed an extraction query with keywords related to rosacea, eczema, vitiligo, acne or psoriasis. All public posts available on the web, containing one of the disease relevant keywords, posted in the defined time span frame analysis, were identified and extracted using the Brandwatch extractor.<sup>19</sup> Then, the identified posts were downloaded along with metadata such as posts' date or web user pseudonym. The resulting data set underwent further cleaning to exclusively obtain testimonies of patients and caregivers affected by these skin diseases. This was performed using a machine learning algorithm, build prior to this work,<sup>20</sup> that identified posts related to patients' and caregivers' experiences. Only posts labelled as patients or caregivers were kept. Then, manual review was performed to exclude false positives. The resulting posts constituted the analysis data set.

# **Ethical consideration**

By design, this study only included open data, publicly available on the web. Private groups, closed forums, profiles information and personal conversations were not accessed. Because of social platforms terms and condition of usage, users give consent for data re-use purposes. This study positions itself as such and is part of the re-use of publicly available secondary data, patient identity was never available for any of the investigators, and GDPR (General Data Protection Regulation) compliance insurance and guidelines were the one followed to pursue this study. Furthermore, gathering consent from all users for their retrospective data re use was to be considered: Indeed, patient consent based on their acceptance of terms that consider their public messages as open data aligns with the concept of data anonymization. However, gathering consent from all individual were to be considered in light of the GDPR, considering principle like data minimization, as the strategy of avoiding personalized identification to seek consent is in line with GDPR's restrictions on targeted contact.

# DATA ANALYSIS

# Analysis of French open experiences and discussions, main themes of public discussions

In order to identify the topics of discussion, the verbatims in patients' and caregivers' posts were analysed using a natural language processing and text mining approach called Biterm Topic Modelling (BTM).<sup>21</sup> Using Biterm Topic Modelling (BTM) algorithm on the whole dataset of the five diseases (patients and caregivers), posts were clustered according to their topics of discussion. Because several topics can be addressed in the same message, some messages can be present in more than one category, resulting in a sum greater than 100%.<sup>21,22</sup>

# **Encountered difficulties**

In order to identify patients' and caregivers encountered difficulties and unmet needs, data saturation method<sup>23-25</sup> was used to obtain a representative set of expressed difficulties, identified by annotators (healthcare professionals, that is pharmacists specialized in social media listening). Encountered difficulty analysis and co-occurrences analysis

were performed for all five dermatoses mutualized, in order to generate a global understanding of the burden of skin diseases; then, for each illness to bring light to specific challenges for each dermatosis.

# RESULTS

#### Description of the population and posts

The extraction yielded a total of 181,750 messages related to at least one of each dermatosis. Then, data cleaning, and identification of patients' and caregivers' verbatims, enabled the composition of the analysis dataset, composed of 20,282 messages (Table 1).

The messages were retrieved from open forums, blogs and social media. As mentioned before, two algorithms were used; the first, a machine learning algorithm classified posts according to the lived medical experience in two categories: patient or caregiver. Then, based on information present in the post, another algorithm was in charge of gender detection, when indicated by the author (Table 2).

Twitter was the top source of posts, for all datasets. Distribution of posts per source varied according to the disease; for example, Babycenter, which is a web community discussing topics about newborns, was highly represented in eczema sources. Youtube was more represented in rosacea and acne, as it includes dermatological videos where youtubers post feedback regarding skin routines and products testing, generating reactions in the comment section. Carenity is a medical forum, which stands out in the eighth position for its psoriasis-specific channels of discussion (Figure 1).

For each dermatosis, top 10 sources, posts distribution and author categorization are detailed in Tables S1–S5.

# Themes of discussion

The most frequent discussion theme discussed by patients and caregivers was the 'Impact on self-image and selfconfidence' (23.66%), the second was 'Generic discussion about therapeutics' (23.32%), and the third was about the 'Burden of others' gaze' (12.81%) (Table 3).

TAI	BLE	1	Distribution	of posts	by co	orpus.
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Corpus	Posts (n)
Acne	12,799
Eczema	4522
Psoriasis	1938
Vitiligo	771
Rosacea	252
Total	20,282

	Eczema		Rosacea		Vitiligo		Acne		Psoriasis	
Category	Patients	Caregivers	Patients	Caregivers	Patients	Caregivers	Patients	Caregivers	Patients	Caregivers
Women	1.492(48.45%)	455 (66.81%)	105 (47.72%)	0 (0%)	288 (46.1%)	30 (41.66%)	6.757 (65.91%)	239 (67.70%)	698 (50.07%)	77 (63.11%)
Men	802 (26.04%)	111 (16.29%)	61 (27.72%)	2 (66.67%)	165 (26.4%)	17 (23.61%)	1.701 (16.59%)	58 (16.43%)	347 (24.89%)	24 (19.67%)
Unknown	785 (25.49%)	115 (16.88%)	54 (24.54%)	1 (33.33%)	172 (27.52%)	25 (34.72%)	1.793 (17.49%)	56 (15.86%)	349 (25.03%)	21 (17.21%)
Total	3.079~(100%)	681 (100%)	220 (100%)	3 (100%)	625 (100%)	72 (100%)	10.251 (100%)	353 (100%)	1.394~(100%)	122 (100%)

TABLE 2 Declared gender of patients and caregivers



FIGURE 1 Top 10 distribution of sources, all dermatoses.

**TABLE 3**11 main topics of discussion in the whole data set (fivedisease and patients and caregivers).

Topic name	Relative frequency
Impact on self-image and self-confidence	23.66%
Generic discussion about therapeutics	23.32%
Burden of others' gaze	12.81%
Autoimmune and chronic character of the dermatoses or other illness	10.68%
Skin impact of hormonal disruption due to the contraceptive pill	9.89%
Newborn's eczema management	8.42%
Description of skin condition and dermatological symptoms	8.07%
Cosmetic products and daily skin routine	6.11%
Psoriatic arthritis	2.05%
Cutaneous side effects of ovarian cycle and pregnancy	1.93%
Natural skin remedies	1.0%

Analysing all topics, two major categories emerged. A category for generic topics (non-disease-specific topics, but with mention of at least one of the five dermatoses), such as the burden of skin disease and the associated impact on self-confidence, discussions about dermatological treatments, the aetiologies and chronicity of the dermatoses, the description of dermatological conditions and symptoms, and the cosmetic products usable by the online community, with a specific focus for the natural remedies. Yet, disease-specific topics also emerged from automatic topic modelling: the management of newborns' eczema, and the discussion focusing on the arthritic complication of psoriasis; furthermore, skin impact of hormonal disruption due to the contraceptive pill in women and cutaneous side effects of ovarian cycle and pregnancy related to acne flare-up is commonly discussed.

# Common and specific encountered difficulties and unmet medical needs

All dermatoses included 487 posts contained at least one encountered difficulty by either a patient or a caregiver, directly related with the skin disease.

The difficulty most expressed, for all five diseases, is the fear of/and management of symptoms. The second most encountered difficulty is the psychological impact (loneliness, depression, anxiety, stress, fear). The distressing nature of the disease is associated with damage to self-image, which is the third most frequently mentioned difficulty. Wandering, the therapeutic impasse and the ineffectiveness of pharmaceutical/dermatological products are expressed by patients, as the fourth most important difficulty; the communities exchange on the products and their temporary effectiveness. The fifth difficulty is the progression of the diseases evolving by relapses that are beyond the control of the patients.

A mixed analysis of top 10 encountered difficulties is displayed in Figure 2, with relative proportion of each disease corpus among the difficulty.

To summarize, for each dermatosis the take-away insights are developed below. Each proportion associated with the mentioned difficulties is the relative proportion of the disease, in the joined analysis.

In eczema, wandering and therapeutic impasse (30%), with the fear and management of flare-ups (30%), are the majority. The loss of effectiveness of dermocorticoids is reported. The impact on daily activities (26%) mainly concerns the quality of sleep as well as eating, which is disrupted in infant eczema, as reported by their relative.

For rosacea, a need for information on laser treatment (50%) is mainly expressed by patients. Its effectiveness, its cost and the number of sessions are source of interrogation for the patients who seek answers. Then, the demand for feedback (31%) is particularly important because each rosacea's profile is different in terms of reaction to products. Fear



**FIGURE 2** Top 10 most mentioned difficulties. Distribution of difficulties by disease.

of blushing and anxiety towards visibility of flare-ups are also a specific pain point expressed in rosacea.

For vitiligo sufferers, acceptance of the disease is a difficulty, represented at 58% in the according difficulty. They deplore the lack of knowledge of the disease, which adds to the burden of others' gaze. The fear and management of depigmentation (41%) being the main symptom, patients mention the affected areas, the difficulty to slow down the progression and the associated fears.

Fear and management of adverse effects (53%) is the majority in acne. Concerns relate to antibiotic therapy, retinoic acid and vitamin A derivatives and contraceptive pills prescribed for acne. Negative self-image (42%) is a difficulty during outbreaks, in messages that express seeking a solution or to express a negative state of mind such as self-loathing.

Psoriasis meets all the difficulties in a rather homogeneous way. The psychological impact (20%) is much more important than difficulties related to self-image (6%). Fear of/and management of symptoms (36%), fear of/and management of flare-ups (26%) and treatment wandering (20%) form a backdrop of difficulties without any one being particularly over- or under-represented. Patients also mention the vicious circle between stress and psoriasis.

Following this mutualized analysis of a global top 10 difficulties, co-occurrences of difficulties, 2-by-2, among messages in each corpus were performed by computer. A data visualization of all five dermatoses co-difficulties is displayed in Figure 3; this visualization displays only the strongest connections between two difficulties, the lack of line between two difficulties does not mean that no connection was found in social media testimonies, as only the strongest were displayed in order to optimize data visualization readability and interpretation (cut-off value was '2' as correlation between difficulties mentioned within less than 2 messages was not included). The width of connections in the figures is a visual indicator of the relative importance of difficulties co-occurrences, with stronger ones being thicker than weaker ones. Thus, we can see that flare-ups management for almost all dermatoses are linked to psychological impact, or difficulties with symptoms management. At this point, specificities are notable such as seeking additional medical advice, connected with therapeutic wandering in Rosacea.

For each dermatosis, we found similar difficulties as in the joint analysis; however, specificities for each skin disease have emerged.

Eczema's encountered difficulty co-occurrence is presented in Figure 4.

- Eczema is the only disease for which we identified that an impact/difficulty extends to relatives. This is an energy-consuming accompaniment, a source of anxiety and questioning. This is explained by the posts of mothers regarding their newborn's eczema.
- 2. Similarly, the impact on daily activities concerns the way in which the symptoms disrupt the infant's sleep or diet, which must be modified.

Rosacea's encountered difficulty co-occurrence is presented in Figure 5.

1. Social anxiety due to blushing causes patients to modulate certain activities to avoid embarrassment.



**FIGURE 3** Co-occurrence analysis of encountered difficulties in all corpora.



**FIGURE 4** Co-occurrence analysis of encountered difficulties in the eczema corpus (the width of the lines reflects the relative importance of the co-occurrence).

- 2. The need for feedback is caused by therapeutic wandering and individual reaction to products. Patients are looking for profiles to identify with. They are also looking for feedback on the laser treatment, its effectiveness, its price and the number of sessions.
- 3. Some messages mention the need to reconsult for another medical opinion, in connection with a diagnostic errancy. Messages mention the lack of recognition of rosacea by the health professional.

Vitiligo's encountered difficulty co-occurrence is presented in Figure 6.

- 1. In vitiligo, the psychological impact is directly linked to the symptoms that disrupt the self-image, against a backdrop of a difficulty in accepting the disease and the weight of the gaze of others.
- 2. Depigmentation is the main symptom mentioned, associated with a fear of the progression of depigmented areas.



**FIGURE 5** Co-occurrence analysis of encountered difficulties in the rosacea corpus (the width of the lines reflects the relative importance of the co-occurrence).



**FIGURE 6** Co-occurrence analysis of encountered difficulties in the vitiligo corpus (the width of the lines reflects the relative importance of the co-occurrence).

Acne's encountered difficulty co-occurrence is presented in Figure 7.

- 1. The difficulties regarding self-image are particularly linked to the psychological impact of acne, because of the pimples that are always present and can worsen during outbreaks.
- 2. The need for feedback is linked to the search for information on treatment, particularly on contraceptive pills and antibiotics. Patients and their mothers are at the origin of this need; the balance of therapeutic benefit vs risk of undesirable effects is at the heart of the questioning.
- 3. The difficulty of therapeutic wandering is frequently mentioned with the fear and management of adverse effects



**FIGURE 7** Co-occurrence analysis of encountered difficulties in the acne corpus (the width of the lines reflects the relative importance of the co-occurrence).



**FIGURE 8** Co-occurrence analysis of encountered difficulties in the psoriasis corpus (the width of the lines reflects the relative importance of the co-occurrence).

within the patients' messages. After having tried various products without success, wandering patients or their relatives, consider treatments perceived as 'stronger' (i.e. antibiotic, retinoids) but wish to seek the opinion of other patients beforehand.

Psoriasis' encountered difficulty co-occurrence is presented in Figure 8.

- 1. Patients express the burden of the vicious cycle of stress and psoriasis flare-ups. The fact that stress triggers flareups and that these flare-ups are in turn a source of stress. The mental health aspect is to be considered to try to stop this vicious circle.
- 2. In fact, especially for patients who are wandering in and out of treatment, the ineffectiveness of treatments is also linked to the fear and management of relapses.

Biotherapies are described by some as a solution and a newfound freedom.

3. The use of alternative medicines, in particular magnetizers, is both envisaged and described by patients in therapeutic wandering.

#### DISCUSSION

#### **Principal findings**

All insights identified in the study come from direct, genuine, patient-centric free testimonies that highlight skin disease's patient sufferance. Firstly, psychological difficulties, manifesting as impacted self-image, anxiety, loneliness or discouragement, are at the core of patient experience of skin condition. The results of this study concurred that emotional distress that comes with dermatoses are a real heavy burden for patients. Patients express great difficulties linked to therapeutical errancy or product ineffectiveness or tachyphylaxis. Internet users are more interested in finding solutions than in describing the impact of illnesses. The analysis of discussed topics offered insights into patients' perceptions; it revealed a burden to live with a skin condition: the weight of other's gaze, the associated impact on self-confidence and the lack of response to treatments. These information are valuable for understanding dermatoses. A need for feedback on treatments is very much in demand by the online communities. The quest for the 'miracle treatment' is really expressed by all patients. Although some of the results of this study are consistent with some of the data in the scientific literature<sup>1,6-10</sup>, others may differ. As this is an innovative method of capturing patients' voices directly, these new learning can complement the knowledge provided by more traditional studies. It is interesting to note that the volume of messages is not proportional to the prevalence of diseases in the general population. Furthermore, the results of these analyses can have a secondary use, which can enrich the dialogues between health stakeholders, notably health professionals or patient associations. Although other social media studies on patients suffering of dermatosis exist,<sup>26,27</sup> they remain rare. This highlights the lack of data on such patients and platform, despite the importance of the necessary patient-centric approach. Indeed, social media data could enrich the understanding of patient's healthcare pathways, and be used by stakeholders and healthcare professionals to tailor medical information, to be adapted to patients' interrogations and demands.

# Limitations

We recognize some limitation related to our study. Firstly, only French verbatims on a 3-year-time span were included in the analysis. Because of by-design infodemiology studies' limitations, only patients with Internet access who are capable, knowledgeable and willing enough to post messages on social media were potentially included. This sample might not be representative of general population affected by a dermatosis, mostly knowing that patients' associations federate online private communities, it would be of interest to include these patients' representatives upstream in order to better grasp patients' reality. Indeed, what patients tell publicly on social media can be different from what they express in private, with patients' associations or even with their health practitioners. Due to ethical and data privacy reasons, our study included only openly accessible online networks and as a result could have lack of potentially relevant information.

# Conclusion

Consistent with the results of the scientific literature, this infodemiology, mixing quantitative and qualitative analysis, is of relevance to ascertain patients' experiences. Patients express generic and very specific pain points and unmet needs. These results should be considered as more proof of patient's difficulties, and be useful to design ways to better manage patients, caregivers, in a tailored way toward their needs. The fight against preconceived ideas is a battle that must continue. Training and education of patients and citizens is fundamental in order to lighten the burden of skin diseases.

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# DATA AVAILABILITY STATEMENT

Research data are not shared.

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#### SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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