SYSTEMATIC REVIEW

Patient perspectives of atopic dermatitis: comparative analysis of terminology in social media and scientific literature, identified by a systematic literature review

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Abstract

Atopic dermatitis (AD) is a chronic skin disease that significantly impacts patient quality of life (QoL). It is unknown whether patients and physicians have the same interpretation of AD burden. Unmet needs and AD disease burden were evaluated by comparing terminology used in social media with terminology used in scientific literature. AD terminology in social media was identified using the NetBase platform, and natural language processing was performed. Topics and words driving negative sentiment were evaluated overall and in relation to specific symptoms. The systematic review of scientific literature identified publications that included AD and QoL terms was identified from PubMed. Term analysis of titles and abstracts was conducted via natural language processing. The occurrence of topics and co-occurrence of words associated with QoL terms were evaluated. More than 3 million social media mentions (2018–2020) and 1519 scientific publications (2000–2020) were evaluated. There were more negative than positive social media mentions, and flare and pain were common symptoms driving negative sentiment. Face and hands were major drivers of negative sentiment in relation to AD symptoms in social media. Sleep and pain were often mentioned together. In scientific literature, pruritus and depression were the most frequently occurring symptoms. Similarly, pruritus was the most common AD symptom co-occurring with QoL terms in the assessed scientific literature. Social media analyses provide a unique view into the patient experience of AD. Symptoms driving negative sentiment in social media appear to be discordantly represented in scientific literature. Incorporating patient perspectives may improve disease understanding and management.
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Conflicts of Interest

J.I. Silverberg is an investigator for Eli Lilly, Kiniksa and Trevi Therapeutics; has received honoraria as a consultant and/or advisory board member for AbbVie, AFYX Therapeutics, Arena Pharmaceuticals, Asana BioSciences, Bluefin Biomedicine, Boehringer Ingelheim, Celgene, Dermavant, Dermira, Eli Lilly, Galderma, GlaxoSmithKline, Incyte, Kiniksa, LEO, Luna Pharma, Menlo Therapeutics, Novartis, Pfizer, RAPT Therapeutics, Regeneron and Sanofi; is a speaker for Pfizer, Regeneron and Sanofi and has received institution grants from Galderma. S.R. Feldman has received research, speaking and/or consulting support from AbbVie, Advance Medical, Almirall, Alvotech, Bristol Myers Squibb, Boehringer Ingelheim, Caremark, Celgene, Eli Lilly, Galderma, GSK/Stiefel, Informa, Janssen, LEO Pharma, Menlo Therapeutics, Merck, Mylan, National Biological Corporation, National Psoriasis Foundation, Novan, Novartis, Ortho Dermatologics, Pfizer, Qurient, Regeneron, Samsung, Sanofi, Sun Pharmaceutical, Suncare Research Laboratories and UpToDate; is a founder and majority owner of www.DrScore.com and a founder and part owner of Causa Research. W. Smith Begolka has received honoraria as an advisory board member for Incyte and Pfizer and is a salaried employee of the National Eczema Association, which has received grants and sponsorship awards from a variety of industry partners (full list: https://nationaleczema.org/about-nea/corporate-supporters). M.B. Johnson and C. Stanojev are employees of ApotheCom, which received payment from Pfizer for analysis and editorial support relating to this publication. M. DiBonaventura, R.

Introduction

Atopic dermatitis (AD) is a chronic, relapsing skin disease with signs and symptoms that include itch, dry skin and skin pain.[1,2] AD can cause sleep and mental health disturbances, leading to increased anxiety, depression, fatigue and, in some cases, suicidal ideation.[3–8] Physician-reported severity of AD symptoms is often incongruous with patient experience, with physicians underestimating severity and impact of disease; this may result from a lack of alignment between burden of individual burden of disease and patient quality of life (QoL).[9–12] Treatment plans offered to patients may not adequately address their symptoms.

Crowdsourcing information from a large number of people via questionnaires or the internet can be used to collect a large volume of patient perspectives and identify research gaps in scientific literature.[13–15] Moreover, advances in artificial intelligence, including natural language processing, facilitate efficient and comprehensive analysis of large amounts of unstructured data (e.g., data collected by crowdsourcing).[16] Themes identified through such methods may differ from academic sources.[13,14,17] Natural language processing of patients' AD experience finds that symptoms, including pain, are linked to both physical and emotional distress.[17] Therefore, natural language processing may provide more comprehensive views of the consequences of AD symptoms on patients' lives beyond those reported in standard patient- and physician-reported measures.

Unlike crowdsourcing using survey questions, social listening captures spontaneous mentions of words or phrases across social media and the internet. Social listening can provide an uncensored view of real-world patient and caregiver experiences of living with a chronic, recurring dermatological disease, which can be compared with findings from scientific literature to expose unmet needs.

The objective of this study was to identify and compare patient experiences of AD as described by social media with the scientific account of AD as described by scientific literature using natural language processing.

Methods

Identification of social media sample

Symplur (Pasadena, CA, USA) and NetBase (Mountain View, CA, USA) platforms were employed for the social listening analysis.[18] Symplur is a social listening platform that provides searchable, detailed coverage of Twitter and actively distinguishes between patient and caregiver users. NetBase offers search and analysis capabilities for social media domains, including blogs, forums, consumer reviews, Twitter, Instagram, Tumblr, Reddit, news and others and previously has been used to quantify interest and sentiment of social media users without distinguishing between patient and caregiver users.[18] NetBase searches were not limited to a specific region.

Social media posts and mentions (see Table S1 for detailed definitions) were evaluated to identify search terms 'atopic dermatitis' and 'eczema' between July 2018 and July 2020; potential misspellings were included. Social media search terms were limited to English. Posts of all languages were included in this analysis, provided that they contained those search terms. Initial searches revealed that NetBase data were inclusive of data captured by Symplur, and therefore NetBase was used for all analyses.

Identification of scientific literature sample

Relevant scientific literature was identified using PubMed/Medline searches of 'atopic dermatitis' and 'eczema' (including synonyms and excluding antonyms identified by Kantor et al.)[19,20] and terms referring to QoL or patient/caregiver-reported information (identified by Kantor et al.[12] and IBM Watson Natural Language Understanding application program interface), limited to English-language articles published between 2000 and 2020 (Table S2). Two reviewers independently reviewed search results to confirm inclusion of only peer-reviewed scientific literature relevant to AD and QoL in human subjects; discrepancies were adjudicated by a third reviewer. A PRISMA diagram of the scientific literature systematic review is shown in Fig. S1.

Titles and abstracts of identified publications were parsed into discrete sentences using Python[21] and were loaded into the IBM Watson Natural Language Understanding application program interface, and topic analysis of each sentence was performed.

Data analysis

For social media analysis, topics and words driving negative sentiment were evaluated overall and in relation to specific AD symptoms. A schematic of this social media sentiment analysis is provided in Fig. 1a. Because there may be multiple mentions, topics, or words per post (e.g., multiple terms per post), posts were used to identify the demographic information and mentions were used for subsequent analyses. To evaluate unmet needs, mentions with negative sentiment were assessed. Net sentiment is a numerical scoring of search results provided by

(a)

(b)
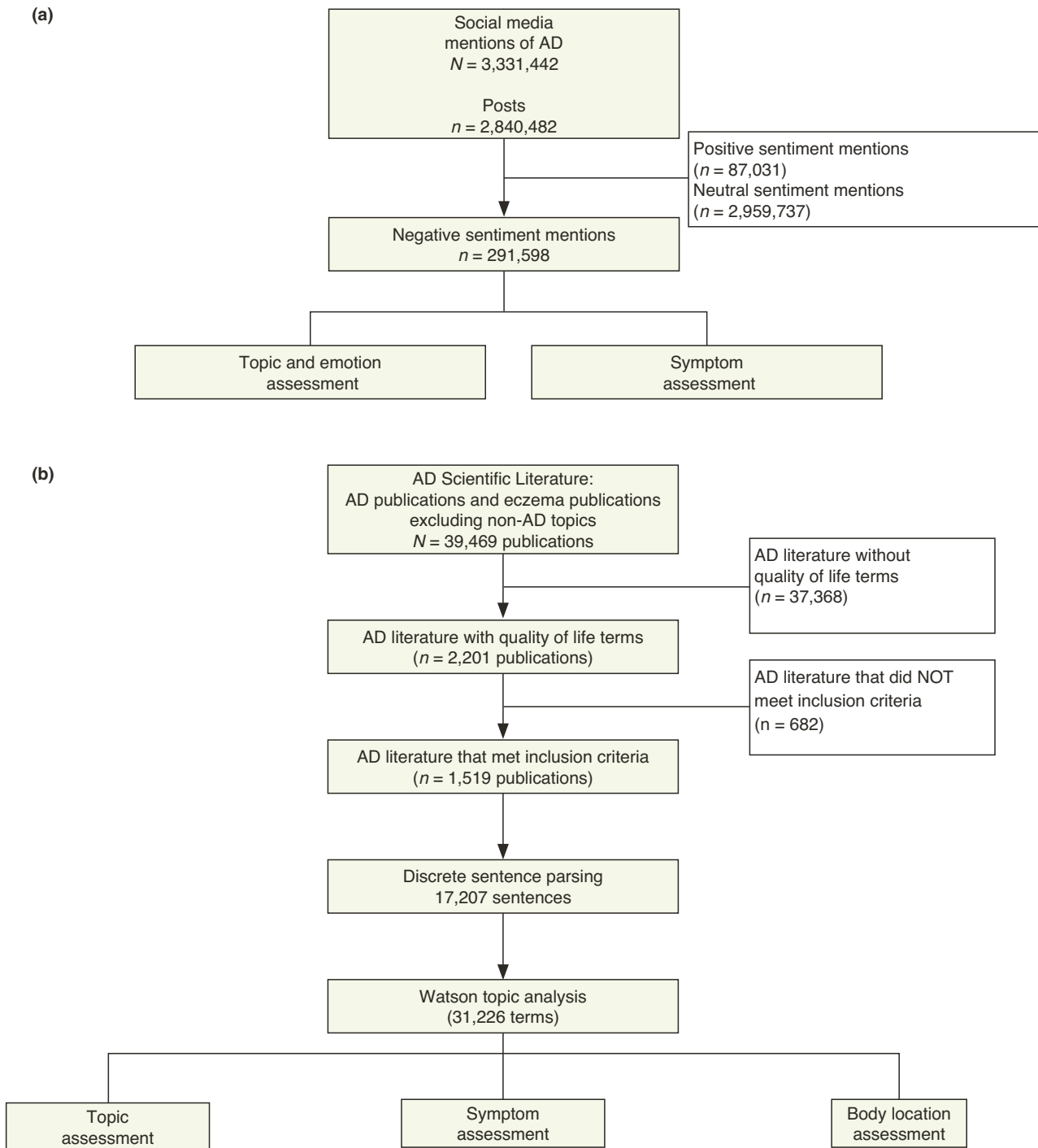
Figure 1 Study design for (a) social media analysis and (b) scientific literature analysis. *AD*, atopic dermatitis.

NetBase that uses a proprietary natural language processing algorithm to assign sentences as having positive, neutral or negative sentiment. Sentences for a topic or set of terms can be aggregated into a single net sentiment score that computes the ratio of positive to negative mentions of a topic. Positivity/negativity is bounded between −100 (of all mentions with valence, 100% are negative) and +100 (of all mentions with valence, 100% are positive).[22] Within mentions with negative sentiment, the 20
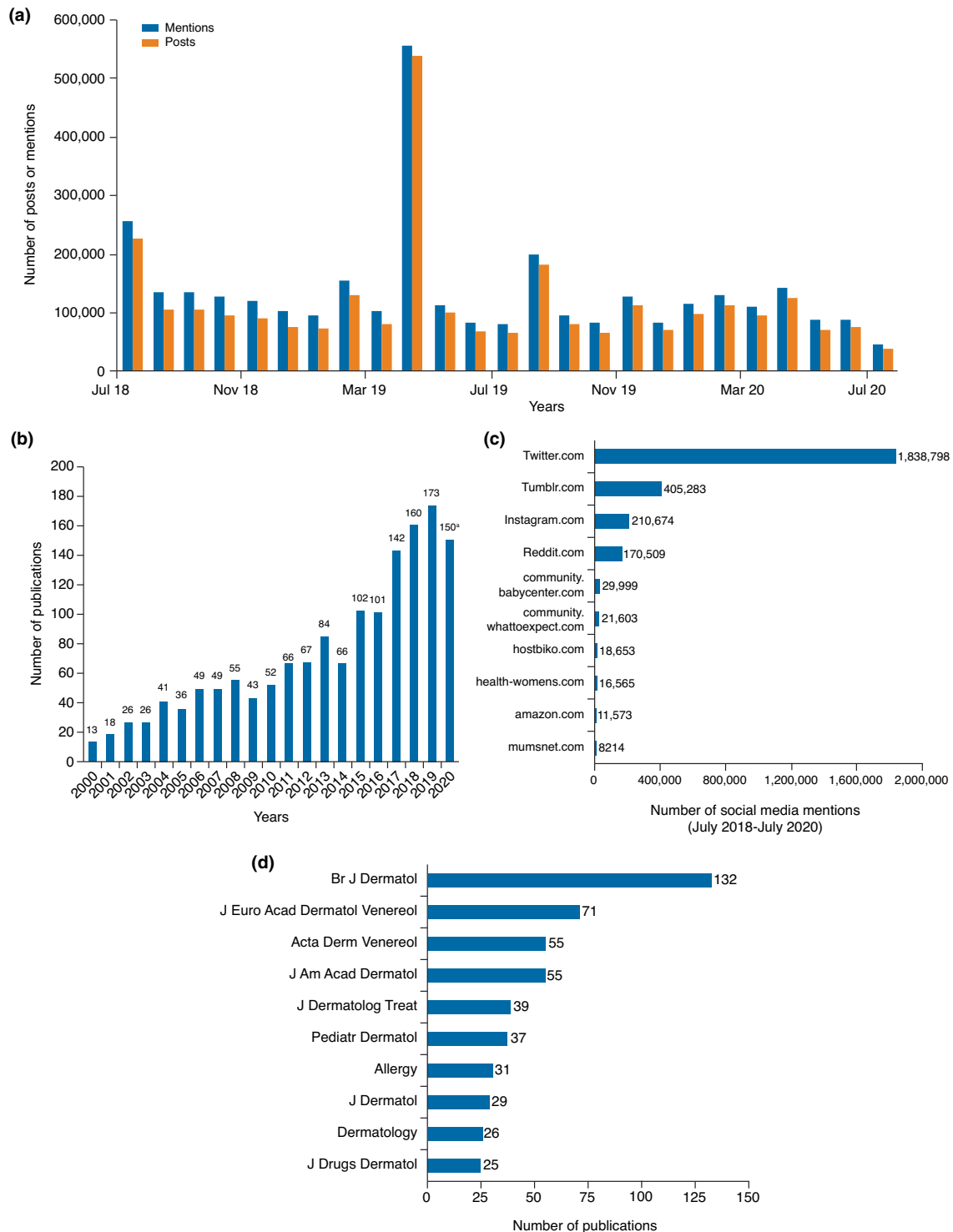
Figure 2 Overview of search results for social media analysis and scientific literature analyses. (b) Social media posts including atopic dermatitis terms between 2018 and 2020; an anomalous peak in social media mentions was observed in April 2019, which can be attributed to the popularity of a single article in *Bloomberg Businessweek* that was responsible for 297 474 posts between April 21 and April 28, 2019. (b) Scientific publications including atopic dermatitis and quality of life terms between 2000 and 2020. (c) Top domains for social media posts. (d) Top journals for scientific publications. [a]The number of publications in 2020 represents only those measured through July 16, 2020.

most prevalent topics and emotions were assessed. To fully encompass the use of each term within the social landscape, every mention was counted even if the same content was reposted by different users.

Within mentions with negative sentiment, words associated with flare, pain, sleep, anxiety, depression and itch also were assessed. In all cases, variants of each symptom term, identified by natural language processing, were aggregated to encompass the entire social conversation. For example, when assessing pain terms, posts that included *pain*, *painful*, *#pain*, *#painful* and *hurts* were evaluated; frequency of words associated with those terms was analysed.

Additional filters were qualitatively identified by human intervention to exclude non-patient sources, including advertising. For example, when assessing terms associated with pain, the pain analysis excluded mentions with the following terms: *renew elastic softness*, *impact quality*, *allergic response*, *inflammation*, *pretty baby*, *CBD* [cannabidiol], *eczema butter* and *eczema honey*. Excluded terms are described for each symptom analysis in the figure legends.

In the scientific literature analysis, terms identified by natural language processing from titles and abstracts were tabulated. A schematic of the study design is provided in Fig. 1b. The 20 most prevalent terms, burden terms and specific symptom-related terms with ≥50 mentions were assessed for frequency. Frequency of terms that co-occurred with QoL also was assessed and is presented as number of occurrences.

Ethical conduct of the study

This protocol was registered according to the International Prospective Register of Systematic Reviews requirements (CRD42021222734 http://www.crd.york.ac.uk/PROSPERO). Study reporting was conducted in accordance with the relevant Enhancing the Quality and Transparency of Health Research (EQUATOR) Network and Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) guidelines.[23]

Results

Overview of social media posts and scientific literature containing atopic dermatitis terms

Social media A total of 2 840 482 posts and 3 331 442 mentions published between July 2018 and July 2020 contained AD terms (Fig. 2a). The social media domain that contained most mentions was Twitter.com (55.2%), followed by Tumblr.com (12.2%), Instagram.com (6.3%) and Reddit.com (5.1%), (Fig. 2c). Authors of social media posts tended to be white (63%) women (68%) aged 25–34 years (20%) (Table S3). Demographic characteristics were available only for a subset of posts; gender data was available for 24% of posts, age and race/ethnicity data was available for 26% of posts. Facebook was not a major contributor to AD posts in this social media analysis because many Facebook posts are designated as private by users. Due to the General Data Protection Regulation, NetBase captures only publicly available social media content.
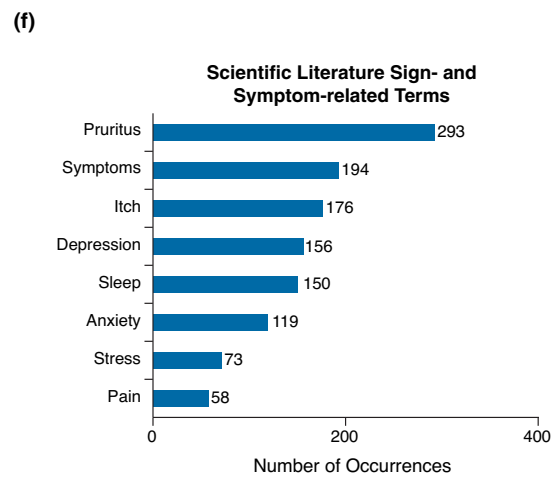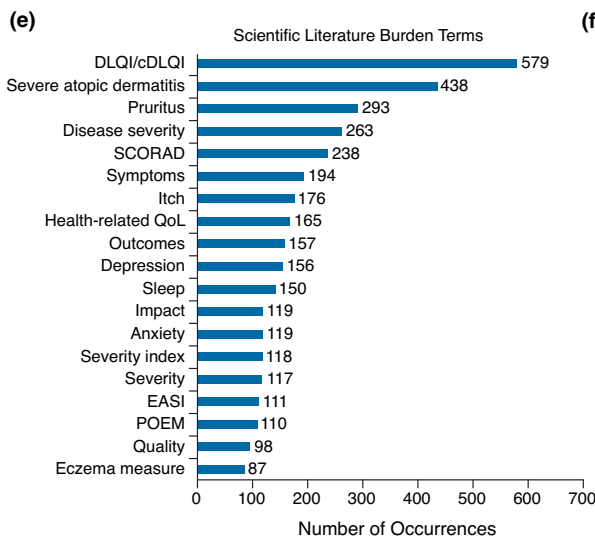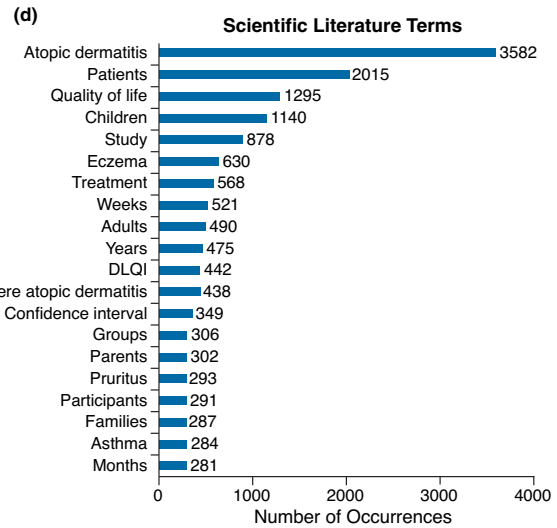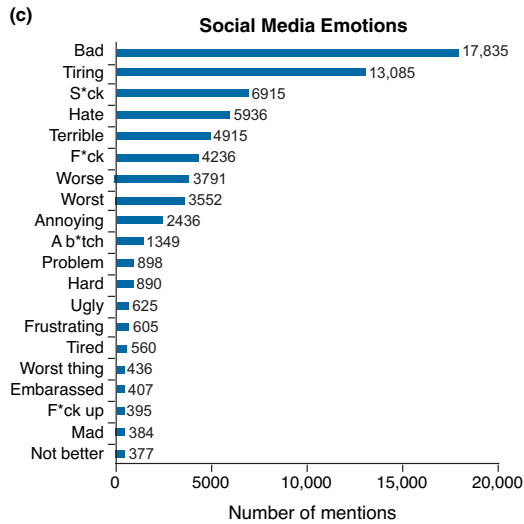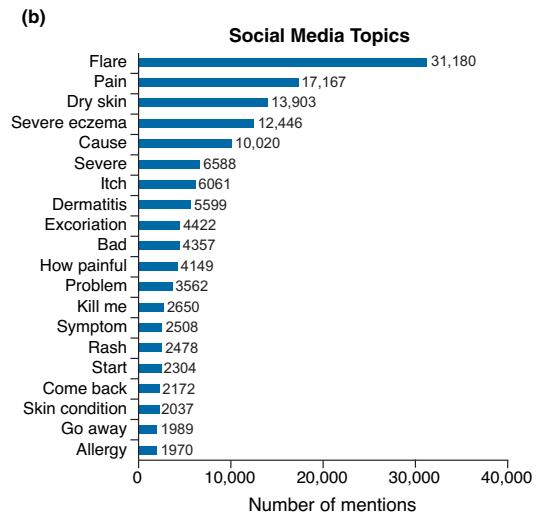
Scientific literature A total of 1519 scientific publications published between January 2000 and July 2020 measured QoL in patients with AD (Fig. 2b). Publications increased from 13 publications in 2000 to 173 in 2019. Between 2000 and 2020, the *British Journal of Dermatology* published the most papers about AD and QoL (Fig. 2d). Author demographics were not available.

Assessment of atopic dermatitis in social media and scientific literature

Social media Because mentions are inclusive of posts, mentions were used for subsequent analyses. No language translations were required. Of mentions containing AD terms, mentions were three times more likely to have negative vs. positive sentiment (291 477 [8.7%] negative vs. 86 994 [2.6%] positive; 2 959 737 [88.7%] were neutral) (Figs 3a and S2a,b). Although sentiment fluctuated (−82% to −35%), sentiment did not appear to significantly improve or worsen over time (Fig. S2c). *Flare* was the topic most frequently associated with negative sentiment and occurred in 31 180 mentions (Fig. 3b). Patient concerns driving negative sentiment included *pain* (17 167 mentions), followed by *dry skin* (13 903), *itch* (6061) and *excoriation* (4422).

The most prevalent emotions driving negative sentiment of AD were *bad* (17 835 mentions), *tiring* (13 085), *suck* (6915), *hate* (5936) and *terrible* (4915) (Fig. 3c). Profanity was also common among mentioned emotions. Qualitatively, references to being tired generally referred to the mental load of eczema and the burden of chronic pain related to AD, rather than an inferred lack of sleep from itch (Fig. S3).

Figure 3 Assessment of atopic dermatitis in social media and scientific literature. Social media (a) sentiment and the (b) topics and (c) emotions driving negative sentiment. Analysis of the most frequently occurring (d) terms, (e) burden terms and (f) signs and symptoms in atopic dermatitis and quality of life scientific literature. In (b), the following terms were combined: *flare/flare up*, *pain/how painful*, *dry/dry skin* and *itchy/itching*. In (d), the following terms were combined: *atopic dermatitis/AD/aD*, *patient/patients*, and *QoL/qoL/QoL/QoL*. In (e), the following terms were combined: *DLQI/dermatology life quality index/dLQI*, *severe atopic dermatitis/severe AD/severe aD*, *outcome/outcomes*, *sleep/sleep disturbance* and *health-related quality of life/hRQoL/quality of life/qoL/QoL/QOL*. In (f), the following terms were combined: *sleep/sleep disturbance*. *AD*, atopic dermatitis; *DLQI*, Dermatology Life Quality Index; *EASI*, Eczema Area and Severity Index; *HRQoL*, health-related quality of life; *POEM*, Patient-Oriented Eczema Measure; *QoL*, quality of life.

(a)

3,331,442

Mentions

Positives	87,031	2.6%
Negatives	291,598	8.7%
Neutrals	3M	88.7%

(b)

Social Media Topics

Topic	Number of mentions
Flare	31,180
Pain	17,167
Dry skin	13,903
Severe eczema	12,446
Cause	10,020
Severe	6588
Itch	6061
Dermatitis	5599
Excoriation	4422
Bad	4357
How painful	4149
Problem	3562
Kill me	2650
Symptom	2508
Rash	2478
Start	2304
Come back	2172
Skin condition	2037
Go away	1989
Allergy	1970

(c)

Social Media Emotions

Emotion	Number of mentions
Bad	17,835
Tiring	13,085
S*ck	6915
Hate	5936
Terrible	4915
F*ck	4236
Worse	3791
Worst	3552
Annoying	2436
A b*tch	1349
Problem	898
Hard	890
Ugly	625
Frustrating	605
Tired	560
Worst thing	436
Embarassed	407
F*ck up	395
Mad	384
Not better	377

(d)

Scientific Literature Terms

Term	Number of Occurrences
Atopic dermatitis	3582
Patients	2015
Quality of life	1295
Children	1140
Study	878
Eczema	630
Treatment	568
Weeks	521
Adults	490
Years	475
DLQI	442
Severe atopic dermatitis	438
Confidence interval	349
Groups	306
Parents	302
Pruritus	293
Participants	291
Families	287
Asthma	284
Months	281

(e)

Scientific Literature Burden Terms

Term	Number of Occurrences
DLQI/cDLQI	579
Severe atopic dermatitis	438
Pruritus	293
Disease severity	263
SCORAD	238
Symptoms	194
Itch	176
Health-related QoL	165
Outcomes	157
Depression	156
Sleep	150
Impact	119
Anxiety	119
Severity index	118
Severity	117
EASI	111
POEM	110
Quality	98
Eczema measure	87

(f)

Scientific Literature Sign- and Symptom-related Terms

Term	Number of Occurrences
Pruritus	293
Symptoms	194
Itch	176
Depression	156
Sleep	150
Anxiety	119
Stress	73
Pain	58

Scientific literature   Titles and abstracts of AD QoL publications were split into discrete sentences, which yielded 17 207 sentences, and term analysis was performed.

The most prevalent terms in the AD scientific literature were *atopic dermatitis* (3582 occurrences), *patients* (2015) and *quality of life* (1295) (Fig. 3d). Burden terms with highest occurrence included *children's Dermatology Life Quality Index (cDLQI)/DLQI, severe atopic dermatitis* and *pruritus*, with 579, 438 and 293 occurrences, respectively (Fig. 3e); *itch* occurred 176 times. Following *pruritus* and *itch*, the most prevalent terms related to patient concerns in scientific literature were *depression, sleep* and *anxiety*, which occurred 156, 150 and 119 times, respectively (Fig. 3e). Of patient concerns that were evaluated, *pain* was the least-mentioned sign/symptom (58 occurrences). Mentions of *pruritus* and *itch* were more frequent than mentions of *pain* (Fig. S4). Flare-related terms (e.g., *flare/flares, exacerbation, recurrence* and *relapse*) each occurred less than 50 times.[24] *Hand/hand eczema* was mentioned 57 times; no other terms related to specific body locations were prevalent.

Terms associated with signs and symptoms of atopic dermatitis in social media

For the following analysis, word clouds were used to identify terms associated with AD signs and symptoms of interest. Topic analysis identifies the primary topic in a given mention, rather than counting instances of every term. To fully encompass the social conversation regarding a given term, term counts, rather than topic analysis, were used.

In social media mentions related to flare (*flare, flare up* and *#flareup*), terms most frequently associated with negative sentiment were *severe eczema* and *severe* (3843 and 3203 mentions, respectively). Comparatively, terms related to specific signs and symptoms of AD had low prevalence, with *itchy, stress* and *burn* having 352, 331 and 272 mentions, respectively. *Flare up on face* was mentioned 193 times (Fig. 4a).

In social media mentions about pain (*pain, painful, #pain, #painful* and *hurts*), *help* (4466 mentions), *sleep* (4009) and *itching* (3951) were common in negative mentions of pain (Fig. 4b). *Flare up* was less common (957 mentions) yet appeared in the top 20 terms. *Hands* were mentioned 1504 times. In mentions about sleep (*sleep, #sleep* and *sleeping*), terms most associated with negative sentiment were *pain/painful* and *itch/itching* with 7476 and

4333 mentions, respectively (Fig. 4c). *Hands* and *flare up* were among common mentions (615 and 601 mentions, respectively).

In mentions related to depression (i.e., *depressing, depressed, killing me, kill me, miserable, sad, unhappy, #depressed, #killme, upset, emotional, crying, cry, losing it, #sad, depresses me, depress me* and *#miserable*), *flare up* was the only symptom-related term in the top 20 terms, with 700 mentions (Fig. 4d). *Miserable, embarrassing* and *anxious* were also commonly mentioned. Specific body parts associated with depression included *face*, with 532 mentions. In social media mentions about anxiety (*anxious, #anxious, anxiety* and *#anxiety*), *flaring* and *am depressed* were commonly mentioned, with 818 and 521 mentions (Fig. 4e). *Embarrassing* and *gross* were also in the top 20 words driving negative sentiment (509 and 272 mentions).

Negative sentiment drivers associated with itch/itching were evaluated. After filtering out advertising, approximately 14% of posts remained, which was not adequate for subsequent term analyses by NetBase. Human intervention confirmed that most mentions of *itch* were in advertisements (e.g., patient testimonials) and were not representative of mentions by patients/caregivers.
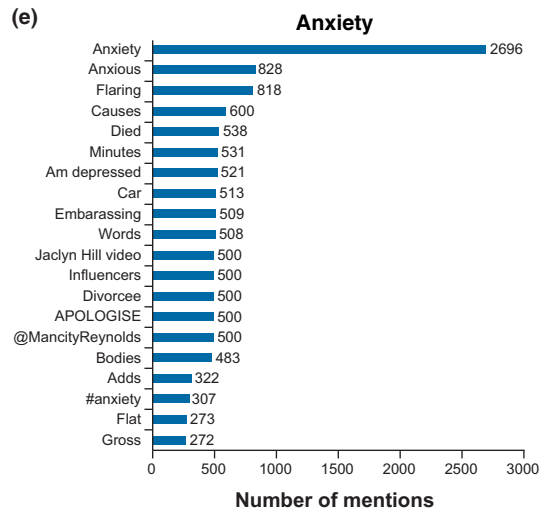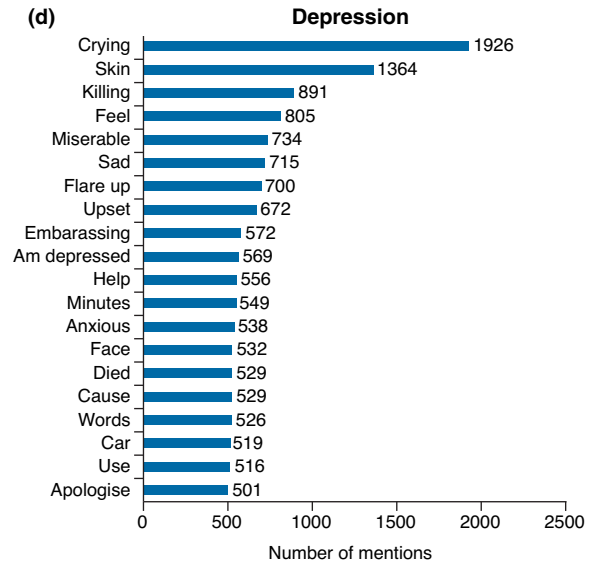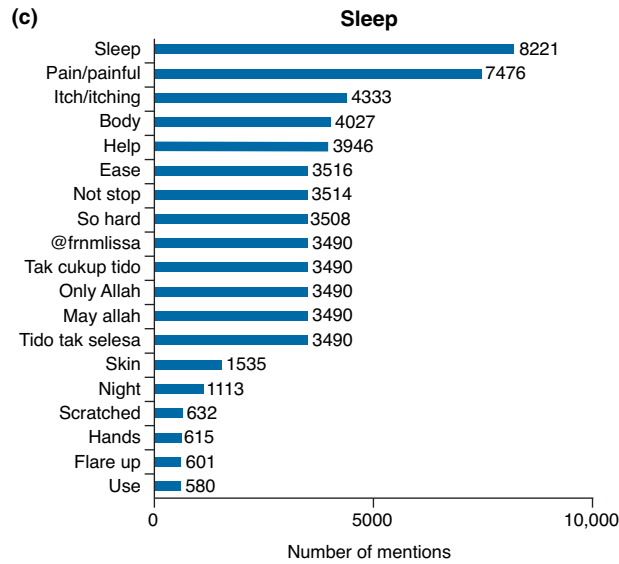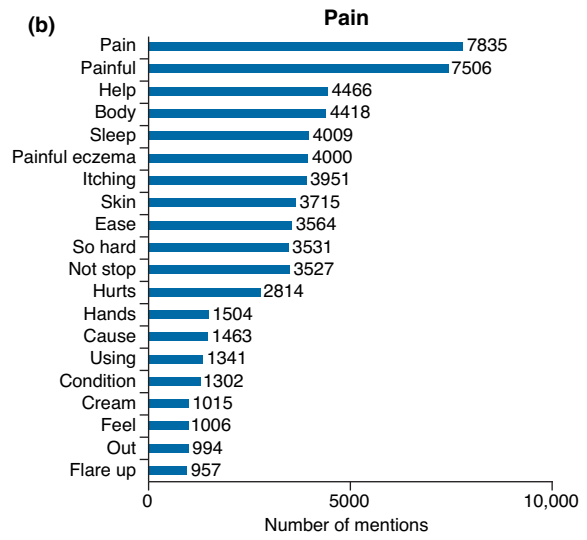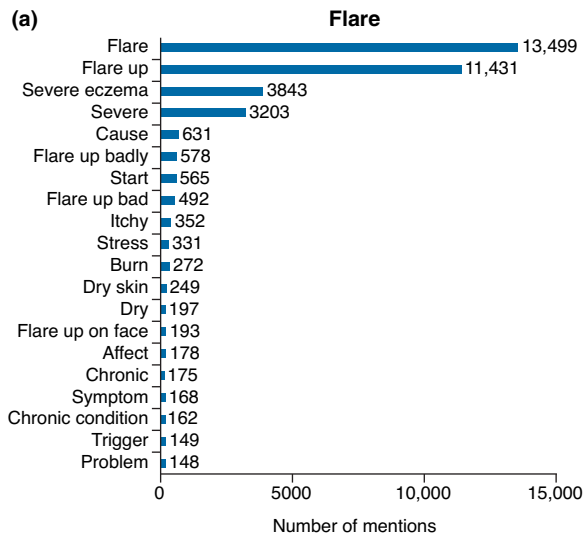
Terms that co-occurred with quality-of-life terms in the atopic dermatitis scientific literature

To evaluate how QoL is represented in scientific literature, frequencies of terms that co-occurred with QoL terms (*quality of life, qoL, QoL* and *HRQoL*) were assessed (Fig. 5a). Patient burden terms associated with QoL terms were *AD/disease severity, DLQI* and *pruritus*, with 145, 95 and 83 mentions, respectively (Fig. 5b). Beyond the 20 most prevalent terms, *depression, sleep, anxiety, stress* and *pain* co-occurred with QoL: 42, 42, 29, 18 and 13 occurrences, respectively (Fig. 5c). Except for *depression* and *sleep*, which were equally prevalent in the QoL assessment, relative prevalence of symptoms co-occurring with QoL terms was not different than the prevalence of symptoms overall. Composite symptom measurement tools *DLQI, SCORing Atopic Dermatitis* (SCORAD)*, Eczema Area Severity Index* (EASI) and *Dermatitis Family Impact* (DFI) were all mentioned in association with QoL, with 95, 62, 24 and 18 occurrences, respectively.

Discussion

This study evaluated patient and scientific perspectives of AD in social media and scientific literature using artificial intelligence

Figure 4 Terms driving negative sentiment associated with atopic dermatitis symptoms (a) flare (b) pain, (c) sleep, (d) depression and (e) anxiety in social media. In (a), flare terms included *flare, flare up, #flareup* and '*flare up*.' Flare analysis excluded mentions with the terms *renew elastic softness* and *impact quality*. In (b), pain terms included *pain, painful, #pain, #painful* and *hurts*. Pain analysis excluded mentions with the terms *renew elastic softness, impact quality, allergic response, inflammation, pretty baby, CBD, eczema butter* and *eczema honey*. In (c), sleep terms included *sleep, #sleep* and *sleeping*. Sleep analysis excluded mentions with the terms *moderate-to-severe* and *high burden*. In (d), depression terms included *depressing, depressed, killing me, kill me, miserable, sad, unhappy, #depressed, #killme, upset, emotional, crying, cry, losing it, #sad, depresses me, depress me* and *#miserable*. Depression analysis excluded mentions with the terms *#ad, pretty baby* and *impact quality*. In (e), anxiety terms included *anxious, #anxious, anxiety* and *#anxiety*. Anxiety analysis excluded mentions with the term *CBD. CBD*, cannabidiol.

(a)

Flare

Flare	13,499
Flare up	11,431
Severe eczema	3843
Severe	3203
Cause	631
Flare up badly	578
Start	565
Flare up bad	492
Itchy	352
Stress	331
Burn	272
Dry skin	249
Dry	197
Flare up on face	193
Affect	178
Chronic	175
Symptom	168
Chronic condition	162
Trigger	149
Problem	148

Number of mentions

(b)

Pain

Pain	7835
Painful	7506
Help	4466
Body	4418
Sleep	4009
Painful eczema	4000
Itching	3951
Skin	3715
Ease	3564
So hard	3531
Not stop	3527
Hurts	2814
Hands	1504
Cause	1463
Using	1341
Condition	1302
Cream	1015
Feel	1006
Out	994
Flare up	957

Number of mentions

(c)

Sleep

Sleep	8221
Pain/painful	7476
Itch/itching	4333
Body	4027
Help	3946
Ease	3516
Not stop	3514
So hard	3508
@frnmlissa	3490
Tak cukup tido	3490
Only Allah	3490
May allah	3490
Tido tak selesa	3490
Skin	1535
Night	1113
Scratched	632
Hands	615
Flare up	601
Use	580

Number of mentions

(d)

Depression

Crying	1926
Skin	1364
Killing	891
Feel	805
Miserable	734
Sad	715
Flare up	700
Upset	672
Embarassing	572
Am depressed	569
Help	556
Minutes	549
Anxious	538
Face	532
Died	529
Cause	529
Words	526
Car	519
Use	516
Apologise	501

Number of mentions

(e)

Anxiety

Anxiety	2696
Anxious	828
Flaring	818
Causes	600
Died	538
Minutes	531
Am depressed	521
Car	513
Embarassing	509
Words	508
Jaclyn Hill video	500
Influencers	500
Divorcee	500
APOLOGISE	500
@MancityReynolds	500
Bodies	483
Adds	322
#anxiety	307
Flat	273
Gross	272

Number of mentions

(a)

Scientific Literature Terms

Term	Number of occurrences
Atopic dermatitis	616
Patients	293
Life	152
Families	147
Disease severity	122
Eczema	99
DLQI	95
Adults	84
Pruritus	83
Quality	74
Impact	67
Symptoms	66
SCORAD	62
Parents	62
Studies	59
Treatment	57
Study	55
Years	50
Psoriasis	48
Patients' quality	43

(b)

Scientific Literature Burden Terms

Term	Number of occurrences
AD/disease severity	145
DLQI	95
Pruritus	83
Quality	74
Impact	67
Symptoms	66
SCORAD	62
Severe atopic dermatitis	55
Patients' quality	43
Depression	42
Sleep	42
Itch	39
Anxiety	29
Outcomes	29
Severity	29
DFI	24
Eczema severity	19
Stress	18
EASI	18

(c)

Scientific Literature Sign- and Symptom-related Terms

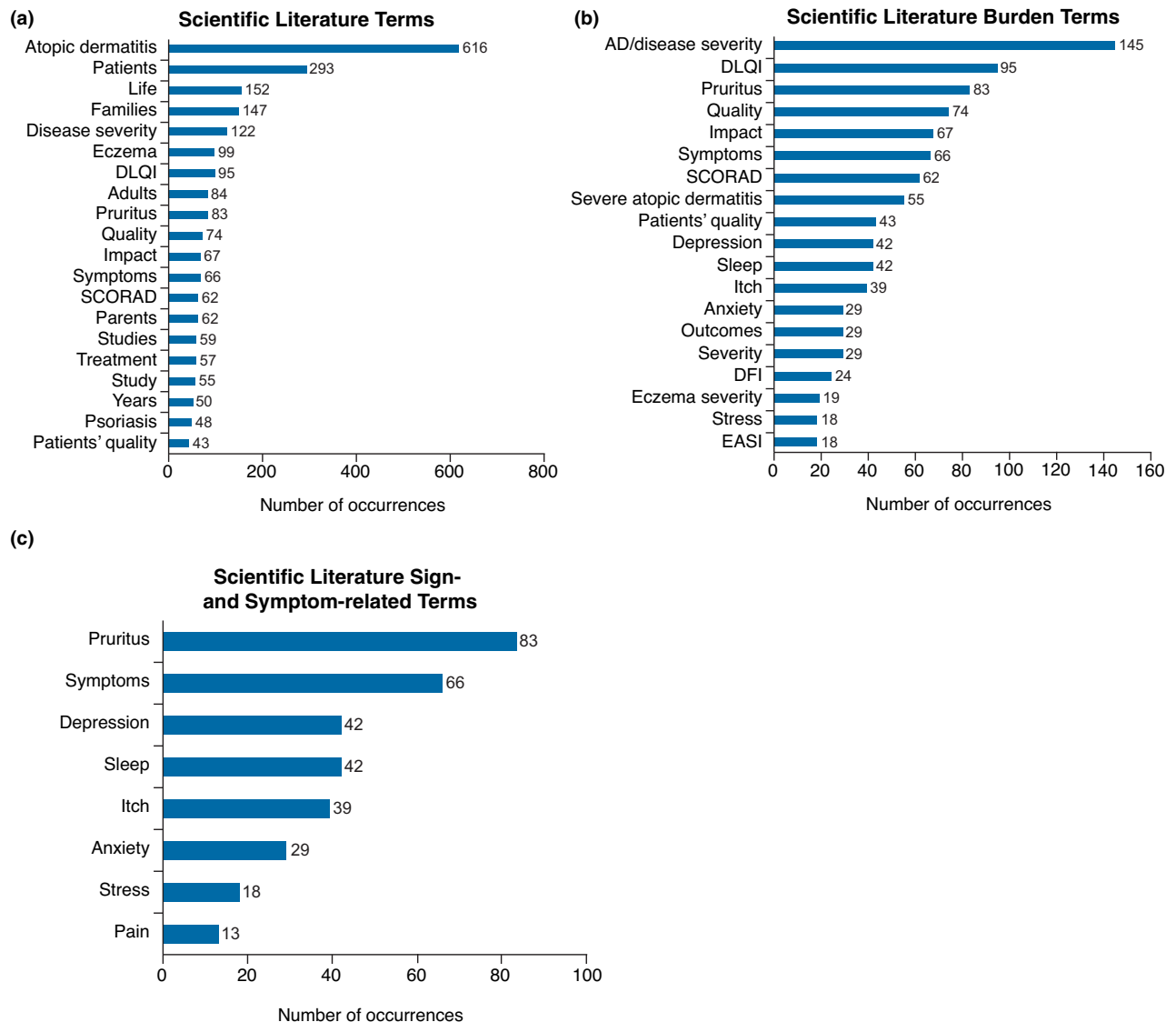| Term	Number of occurrences
Pruritus	83
Symptoms	66
Depression	42
Sleep	42
Itch	39
Anxiety	29
Stress	18
Pain	13

Figure 5 Words associated with quality of life in atopic dermatitis scientific literature. Analysis of the most frequently occurring (a) terms, (b) burden terms, and (c) sign and symptom terms. Quality of life terms included *quality of life*, *qoL*, *QoL*, *QOL* and *HRQoL*. In (b), the following terms were combined: *AD severity/disease severity*; *sleep/sleep disturbance*. In (c), the following terms were combined: *sleep/sleep disturbance*. DFI, Dermatitis Family Impact; DLQI, Dermatology Life Quality Index; EASI, Eczema Area Severity Index; HRQoL, health-related quality of life; QOL, quality of life; SCORAD, SCORing Atopic Dermatitis.

natural language processing. A discordance in the patient terminology related to AD was observed between social media and scientific literature. Flare terms appeared in all the social analyses (i.e., those related to pain, sleep, depression and anxiety), yet flare did not appear as a prevalent term in the AD QoL literature assessed in this study. Although previous scientific studies have identified flare as a significant burden to patients,[25] a recent systematic literature review highlighted that multiple definitions of flare are in use by the scientific community and few incorporate

patient-reported outcomes,[24,26] which may contribute to its low prevalence in the AD QoL literature.

Pain was also underrepresented in AD QoL scientific literature compared with social media. Pain was described as a key symptom in AD in scientific literature late in the study period, which may contribute to this discrepancy.[2,27] Pain has since received interest as a symptom, and a recent natural language processing study in patients with AD has highlighted the relationship between pain and the emotional burden of AD.[17] In the social

media analysis herein, pain was associated with mentions of sleep and vice versa, indicating that pain may be related to sleep-mediated impairment by AD and may contribute to the psychological effects related to sleep impairment.[6,7,28] Additionally, the prevalence of specific body locations as major drivers of negative sentiment in social media symptom analysis but not in scientific literature. Both warrant consideration of lesion location as a measure of disease severity and emphasizes that AD on these anatomical sites may have implications related to overall burden of disease, including reduced daily activities and burden on occupational functions. A graphical abstract and plain language summary of these findings are available in the Supplementary Material.

Although social media search results for *itch* contained a high concentration of advertising, which was prohibitive to subsequent analyses, *itch* did appear as a term driving negative sentiment for other symptoms (i.e., flare, pain and sleep). This result indicates that itch is likely to be bothersome to patients despite the term being co-opted by advertising. Itch terms were extremely prevalent in the scientific literature analysis; past studies and a recent patient-focused drug development meeting indicated that itch may be the most problematic symptom to patients.[15,29]

The prevalence of negative sentiment in social media is consistent with the impact of AD on mental health observed in scientific literature.[30,31] The social conversation provided a rich description of how the emotional impact of AD can be complementary to standardized outcome measures (e.g., SCORAD, DLQI, Patient-Oriented Eczema Measure, EASI). For example, the emotional impact of AD may not be adequately reflected by DLQI, the current preferred QoL assessment tool in AD by international consensus.[32] Although mentions of anxiety and depression were less frequent compared with other patient concerns in social media, the intensity of the sentiment in social media was evidenced by extreme language, including terms like *kill me* and the use of profanity. Together, this intensity reflects the severe impact of the disease on patients and suggests an unmet need for more-effective treatments.

The data presented here add to a growing body of evidence indicating that a gap exists between topics of concern to patients and those covered by the research in scientific literature,[14,17] and underscores an opportunity for collaboration among patients, caregivers, clinicians, and researchers. Social listening provides an unsolicited and uncensored view of the experience of patients with AD. Given the importance of patient-reported outcomes in optimizing disease management,[2,33,34] synthesis of these data provides a novel method by which to measure patient experience that is not captured by standardized outcome measures. While the data presented here require validation from patient questionnaires and focus groups, recent publications of such interviews support the importance of symptoms underrepresented in the scientific literature, such as pain, to patients.[17,35]

There are several limitations of this study. Mentions on Facebook, a major social media platform, were not a large part of the

NetBase data set. Patients who make posts about their negative disease experience may have more severe disease compared with patients who do not make such posts, and thus these sentiments may not be generalizable to all patients with AD. Additionally, negative sentiment drivers in social media mentions about itch were not able to be assessed due to their frequent usage in non-patient sources. It is possible that a lack of precise language in social media, such as the distinction between feelings of emotional and physical pain, could result in conflation of symptoms. A more detailed, qualitative analysis, including patient interviews, may more effectively distinguish the relative burden of physical and emotional symptoms of AD as represented by social media. Comparison between scientific literature analysis and social media analysis may also provide limitations. Scientific literature analysis was limited to titles and abstracts, which are concise by nature and the automated search of the literature has not been validated. Low frequency of specific burden terms (e.g., *burden, emotional burden, social functioning* and *work productivity*) is a limitation of the methodology used in this analysis, and, in the future, use of full-text manuscripts for literature analysis may provide a more nuanced view of burden terms used in scientific literature. Also, it was impossible to determine the demographics of authors. We did not examine whether demographics of patients in scientific literature were comparable to those who communicated on social media. Additionally, the purpose of communication for social media is fundamentally different from that for scientific literature. For example, scientific studies are intended to be objective and therefore lack valence of sentiment that was observed in social media.

Conclusion

Flare and pain are common terms used among patients with AD who make social media posts about the disease. A discordance exists between patient terminology represented in social media and in scientific literature. This discordance supports the importance of the patient perspective and the need to incorporate that perspective into clinical practice and academic work to improve the evaluation, understanding and management of AD.

Acknowledgements

Data availability statement

Upon request, and subject to review, Pfizer will provide the data that support the findings of this study. Subject to certain criteria, conditions and exceptions, Pfizer may also provide access to the related individual de-identified participant data. See https://www.pfizer.com/science/clinical-trials/trial-data-and-results for more information.

References

1 Boguniewicz M, Fonacier L, Guttman-Yassky E, Ong PY, Silverberg J, Farrar JR. Atopic dermatitis yardstick: practical recommendations for an evolving therapeutic landscape. *Ann Allergy Asthma Immunol* 2018; **120**: 10–22.e12.

2 Silverberg JI, Gelfand JM, Margolis DJ *et al*. Pain is a common and burdensome symptom of atopic dermatitis in United States adults. *J Allergy Clin Immunol Pract* 2019; **7**: 2699–2706 e2697.

3 Drucker AM, Wang AR, Li WQ, Sevetson E, Block JK, Qureshi AA. The burden of atopic dermatitis: summary of a report for the National Eczema Association. *J Investig Dermatol* 2017; **137**: 26–30.

4 Silverberg JI. Public health burden and epidemiology of atopic dermatitis. *Dermatol Clin* 2017; **35**: 283–289.

5 Girolomoni G, Luger T, Nosbaum A *et al*. The economic and psychosocial comorbidity burden among adults with moderate-to-severe atopic dermatitis in europe: analysis of a cross-sectional survey. *Dermatol Ther* 2021; **11**:117-130.

6 Ronnstad ATM, Halling-Overgaard AS, Hamann CR, Skov L, Egeberg A, Thyssen JP. Association of atopic dermatitis with depression, anxiety, and suicidal ideation in children and adults: a systematic review and meta-analysis. *J Am Acad Dermatol* 2018; **79**: 448–456.e430.

7 Sandhu JK, Wu KK, Bui TL, Armstrong AW. Association between atopic dermatitis and suicidality: a systematic review and meta-analysis. *JAMA Dermatol* 2019; **155**: 178–187.

8 Kwatra SG, Gruben D, Fung S, DiBonaventura M. Psychosocial comorbidities and health status among adults with moderate-to-severe atopic dermatitis: a 2017 US national health and wellness survey analysis. *Adv Ther* 2021; **38**: 1627–1637.

9 Wei W, Anderson P, Gadkari A *et al*. Discordance between physician- and patient-reported disease severity in adults with atopic dermatitis: a US cross-sectional survey. *Am J Clin Dermatol* 2017; **18**: 825–835.

10 Magin PJ, Pond CD, Smith WT, Watson AB, Goode SM. Correlation and agreement of self-assessed and objective skin disease severity in a cross-sectional study of patients with acne, psoriasis, and atopic eczema. *Int J Dermatol* 2011; **50**: 1486–1490.

11 Torrelo A, Ortiz J, Alomar A, Ros S, Prieto M, Cuervo J. Atopic dermatitis: impact on quality of life and patients' attitudes toward its management. *Eur J Dermatol* 2012; **22**: 97–105.

12 Kantor R, Dalal P, Cella D, Silverberg JI. Research letter: impact of pruritus on quality of life-a systematic review. *J Am Acad Dermatol* 2016; **75**: 885–886.e884.

13 Armstrong AW, Harskamp CT, Cheeney S, Schupp CW. Crowdsourcing in eczema research: a novel method of data collection. *J Drugs Dermatol* 2012; **11**: 1153–1155.

14 Capozza K, Shao Y, Zeng Q. "Crowdsourcing" a patient-centered research agenda for pediatric atopic dermatitis. *Int J Dermatol* 2016; **55**: 1414–1416.

15 McCleary K. More than Skin Deep Report 2020. URL http://www.morethanskindeep-eczema.org/uploads/1/2/5/3/125377765/mtsd_report_-_digital_file.pdf (last accessed: 17 December 2020).

16 Zhu F, Patumcharoenpol P, Zhang C *et al*. Biomedical text mining and its applications in cancer research. *J Biomed Inform* 2013; **46**: 200–211.

17 Falissard B, Simpson EL, Guttman-Yassky E *et al*. Correction to: qualitative assessment of adult Patients' perception of atopic dermatitis using natural language processing analysis in a cross-sectional study. *Dermatol Ther* 2020; **10**: 307–310.

18 Netbase[Computer software]. Version 21.155.0.42e774. Mountain View, CA, USA. NetBase Solutions, Inc. 2020.

19 Kantor R, Thyssen JP, Paller AS, Silverberg JI. Atopic dermatitis, atopic eczema, or eczema? A systematic review, meta-analysis, and recommendation for uniform use of 'atopic dermatitis'. *Allergy* 2016; **71**: 1480–1485.

20 Ayasse MT, Ahmed A, Espinosa ML *et al*. What are the highest yielding search strategy terms for systematic reviews in atopic dermatitis? A systematic review. *Arch Dermatol Res* 2020; **313**: 737–750.

21 Van Rossum G, Drake Jr FL. Python reference manual. Centrum voor Wiskunde en Informatica Amsterdam; 1995.

22 Zhang Y, Desouza P. Enhance the power of sentiment analysis. *Int Schol Sci Res Innov* 2014; **8**: 421–426.

23 Moher D, Liberati A, Tetzlaff J, Altman DG. The PRISMA group. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med* 2009; **6**: e1000097.

24 Langan SM, Thomas KS, Williams HC. What is meant by a "flare" in atopic dermatitis? A systematic review and proposal. *Arch Dermatol* 2006; **142**: 1190–1196.

25 Zuberbier T, Orlow SJ, Paller AS *et al*. Patient perspectives on the management of atopic dermatitis. *J Allergy Clin Immun* 2006; **118**: 226–232.

26 Abuabara K, Margolis DJ, Langan SM. The long-term course of atopic dermatitis. *Dermatol Clin* 2017; **35**: 291–297.

27 Vakharia PP, Chopra R, Sacotte R *et al*. Burden of skin pain in atopic dermatitis. *Ann Allergy Asthma Immunol* 2017; **119**: 548–552 e543.

28 Yu SH, Silverberg JI. Association between atopic dermatitis and depression in US adults. *J Invest Dermatol* 2015; **135**: 3183–3186.

29 Silverberg JI, Gelfand JM, Margolis DJ *et al*. Patient burden and quality of life in atopic dermatitis in US adults: a population-based cross-sectional study. *Ann Allergy Asthma Immunol* 2018; **121**: 340–347.

30 Thyssen JP, Hamann CR, Linneberg A *et al*. Atopic dermatitis is associated with anxiety, depression, and suicidal ideation, but not with psychiatric hospitalization or suicide. *Allergy* 2018; **73**: 214–220.

31 Vittrup I, Andersen YMF, Droitcourt C *et al*. Association between hospital-diagnosed atopic dermatitis and psychiatric disorders and medication use in childhood. *Br J Dermatol* 2021; **185**: 91–100.

32 Barrett A, Hahn-Pedersen J, Kragh N, Evans E, Gnanasakthy A. Patient-reported outcome measures in atopic dermatitis and chronic hand eczema in adults. *Patient* 2019; **12**: 445–459.

33 Patient Centered Outcomes Research Institute. Why PCORI was created. URL http://www.pcori.org/about-us/why-pcori-was-created (last accessed: 17 December 2020).

34 Schmitt J, Spuls PI, Thomas KS *et al*. The Harmonising outcome measures for eczema (HOME) statement to assess clinical signs of atopic eczema in trials. *J Allergy Clin Immunol* 2014; **134**: 800–807.

35 Snyder AM, Taliercio VL, Brandenberger AU *et al*. Effects of pain from atopic dermatitis: interview and focus group study with patients and their families. *JMIR Dermatol* 2021; **4**: e29826.

Supporting information

Additional Supporting Information may be found in the online version of this article:

Figure S1. PRISMA flow diagram for the systematic review of quality of life in atopic dermatitis scientific literature.

Figure S2. Summary of social media sentiment, including (a) most frequent terms by sentiment, (b) word cloud of top emotions, and (c) net sentiment over time.

Figure S3. Examples of social media posts with mentions related to *tiring*.

Figure S4. Terms associated with atopic dermatitis in the scientific literature related to (a) physical symptoms by year, (b) mental health symptoms by year, and (c) symptom measurement tools by year.

Table S1. Key definitions in social media analysis.

Table S2. PubMed search strategy.

Table S3. Demographics of authors of social media posts about atopic dermatitis.

Appendix S1. PRISMA 2020 Checklist.