Title

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Publication Date

2018

PatientsLikeMe® and atopic dermatitis: characterizing the atopic dermatitis patient profile

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Abstract

Introduction: Atopic Dermatitis (AD) is a common dermatologic disorder that affects 17.8 million individuals in the United States. Online medical communities have become increasingly popular over the last several years, providing an additional avenue of therapy for patients.
Purpose: This retrospective analysis looks to characterize the AD patient profile to better assess features of the AD community and appraise PatientsLikeMe data with current AD literature.
Methods: PatientsLikeMe data recorded by April 2018 from persons who reported AD as their primary or secondary diagnosis were included in the analysis.
Results: The PatientsLikeMe database had 410 individuals reporting AD as of April 2018. Of these, 61.46% (252/410) report AD as their primary disease. Of those reporting, 180/199 (90.45%) were diagnosed by a medical professional whereas 19/199 (9.55%) were self-diagnosed. The number of persons recording predefined PatientsLikeMe symptoms are as follows: stress (20), fatigue (132), pain (126), anxious mood (118), and depressed mood (103).
Significance: Patient-oriented medical communities are a valuable resource for those affected by various conditions. Although clinical applications are still uncertain, this data allows practitioners access to profiles self-defined by online users.

Keywords: atopic dermatitis, social media, PatientsLikeMe

Introduction

Atopic dermatitis (AD), also known as atopic eczema, is a chronic, non-infectious skin condition affecting 17.8 million individuals and is the seventeenth most costly dermatologic condition in the United States, costing $314 million annually [1, 2]. In addition, the lifetime prevalence of AD in school-aged children is estimated to be as high as 17% [3].

Atopic dermatitis is characterized by painful, pruritic, erythematous, and scaly skin lesions. Flare-ups may acutely recur and remit, causing weeping and breakage of the epidermal layer with subsequent thickening of the skin. Although AD can occur nearly anywhere on the body, location will vary by gender and age [1]. Alternatively, patients ranging from children to adults may experience dermatitis on the flexural surfaces of their extremities, anterior and lateral neck, eyelids, wrists, face, and dorsa of hands and feet. Notably, it can present concurrently with asthma and allergic rhinitis, commonly known as the allergic triad [1].

Atopic dermatitis is a multifactorial disease process resulting from a constellation of genetic and environmental influences. These afflictions ultimately contribute to variable epidermal thickness, altered acid mantle pH, abnormal skin flora balance, and compromised barrier integrity [4]. Although little can be done to prevent the onset of AD, the mainstay of therapy is avoidance of irritating compounds, barrier emollients, and temporary applications of corticosteroid cream and ointment. In refractory cases, immune modulatory compounds may be initiated [5].

The effects of AD transcend dermatologic considerations and are concomitant in a variety of

comorbidities. In particular, AD patients have an increased risk of developing atopic, psychiatric, and autoimmune disorders [6]. Atopic dermatitis often affects quality of life by making it difficult to sleep, concentrate, or carry out daily activities. Patients may also report embarrassment, anxiety, or depression related to their AD. In a 2015 study, Cheng et al. found that the prevalence rate of psychiatric disorders (i.e. depressive disorders and anxiety disorders) was greater among those with AD [7].

Disease management and whole person wellness-centered care strategies have significantly advanced in the last several years. In particular, disease-centered social networking sites and online communities have provided a unique opportunity for analysis of self-reported disease symptoms and lifestyle assessments. Online communities and forums have become an increasingly popular source for patients to find support and share disease courses [8]. On these sites, user demographics, symptoms, and treatments are shared by users and collated by the site. This paper will characterize the AD patient profile, as reported by users on patientslikeme.com.

Methods

Study population

PatientsLikeMe is an open access database that allows users affected by various conditions to self-report experiences with their respective illnesses. Since April 2011, PatientsLikeMe has been available worldwide, but only in the English language. According to one study, users of PatientsLikeMe found the site through a variety of avenues, including but not limited to, online advertising, media partnerships, press coverage, word of mouth, and physician referral [9]. The analyzed data was extracted from members who reported AD as either their primary diagnosis or a symptom of an additional disease process recorded before April 2018.

Data Collection

In addition to reporting their diagnosis of AD, PatientsLikeMe members are able to report basic demographics including sex, gender identity, and age. Members are encouraged to personalize their profile by writing a bio, sharing their story, and listing their interests. In terms of symptoms, the PatientsLikeMe platform provides a standardized set **of symptoms including "anxious mood," "depressed mood," "fatigue," "pain," and "stress." Of these, users** are able to qualitatively rate the severity of their symptoms as severe, moderate, mild, or none. Treatments and their respective side effects may also be reported. However, there is no standardized list for treatments/side effects, allowing for a wide range of reports. Of note, members may choose to not share a given section of their profile.

Analysis

Data listed by PatientsLikeMe was retrospectively analyzed. Data included users who listed AD as either their primary diagnosis or an association with a comorbid condition.

Results

Patient Characteristics

According to the PatientsLikeMe database, 410 users report having AD as of April 2018. Of these, 61.46% (252/410) claim that AD is their primary condition. In the PatientsLikeMe community, females comprise 61% of reported cases whereas males encompass the remainder 39%. Users ages 30-39 (32.01%) make up the majority of the AD population whereas users ages 40-49 (19.84%) make up the second largest group. The remaining distributions are summarized in Table 1. The site further differentiates users by **"age at first symptom." Of the 143** individuals to share their age at first symptom, 60.84% (87/143) documented that they first experienced AD between

Table 1: *Ages of PatientsLikeMe Members with Atopic Dermatitis*

Age	Number of respondents	Percent of respondents
0 – 19	18	4.76%
20 – 29	72	19.05%
30 – 39	122	32.01%
40 – 49	74	19.84%
50 – 59	56	14.81%
60 – 69	27	7.14%
70+	9	2.38%

Table 2: *Age of First Reported Atopic Dermatitis*

Age	Number of respondents	Percent of respondents
0 – 19	87	60.84%
20 – 29	21	14.69%
30 – 39	16	11.19%
40 – 49	13	9.09%
50 – 59	3	2.10%
60 – 69	3	2.10%
70+	0	0.00%

ages 0-19 (Table 2). In total, of the 199 members to share their diagnosis status, 180 (90.45%) were reportedly diagnosed by a medical professional whereas 19 (9.55%) were self-diagnosed.

Common Symptoms Profile
PatientsLikeMe has a standardized patient profile that allows the user to fill out a predefined list of common symptoms. However, members may opt to not answer one or more of the categories. Responses included stress (20), fatigue (132), pain (126), anxious

mood (118), and depressed mood (103). These categories are further subdivided into severity of **symptoms, allowing the user to record "none," "mild," "moderate," or "severe"** (Figure 1). In addition, Table 3 summarizes the most common therapies users find helpful for each of these symptoms.

Discussion

This assessment of the AD patient profile provides valuable insight into the patient perspective of living with this disease. As these communities evolve, they will continue to be a topic of research as the medical community looks to further serve patients. Although valuable, the reported data may not be completely representative of the general population. This study demonstrates a clear female predominance for reporting AD in this forum. However, this correlation is not as clear in the literature. Although some studies show a slight female predominance [10, 11],
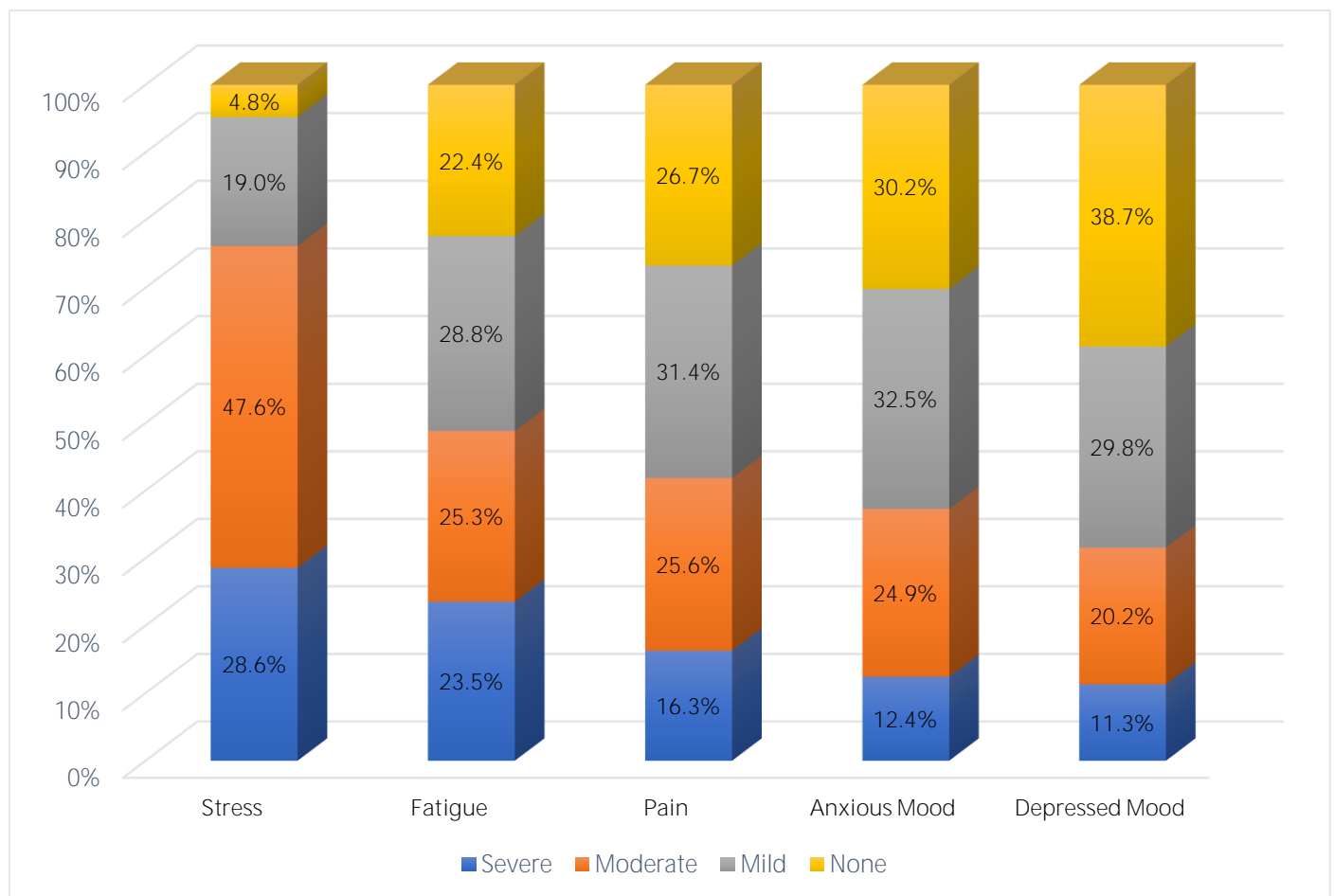

Figure 1. *Distribution of reported symptoms and severity.*

others find no association between AD and gender [12-14]. The discrepancy between data reported online and that found in the literature may be explained by demographics of online health community users [15]. Sadah et al. reports that women ages 30-49 are most likely to participate in online health communities and other social media outlets [15].

Although **PatientsLikeMe provides a "common symptoms" profile and allows the user to rate their symptoms on a scale of "none" to "severe,"** this scale is inherently subjective and may confer a gender bias. Two of the common symptoms reported on **PatientsLikeMe are "anxious mood" and "depressed mood." Moreover, it has also been observed that** females with AD have significantly more disease-related depression/anxiety than males [16]. Provided that 61% of the respondents on the PatientsLikeMe AD profile are female, responses may tip in favor of moderate/severe as opposed to mild/moderate. Furthermore, only 61.46% of the AD database states

Table 3: *Reported Therapies for Predefined PatientsLikeMe Symptoms***

Common symptom	Reported therapies
Stress	1) Listen to music (3) 2) Individual therapy (2) 3) Alprazolam (1) 4) Fourteen other therapies with (1) respondent
Fatigue	1) Modafinil (2) 2) Rest (2) 3) Amytriptyline (1) 4) Seventeen other therapies with (1) respondent
Pain	1) Tramadol (7) 2) Acetaminophen (6) 3) Cyclobenzaprine (5) 4) Ibuprofen (5)
Anxious Mood	1) Clonazepam (8) 2) Buspirone (5) 3) Alprazolam (4) 4) Lorazepam (4)
Depressed Mood	1) Bupropion (4) 2) Duloxetine (4) 3) Sertraline (4) 4) Venlafaxine (4)

** Reported therapies are not necessarily used for atopic dermatitis directly; rather, they are filtered by users who report atopic dermatitis as their primary condition or a comorbid condition)

that AD is their primary diagnosis. The database fails to further stratify AD with regard to the common symptoms reported by the user. This makes it **difficult to assess whether the user's stress, fatigue,** pain, and mood are directly related to AD or an associated comorbidity.

In the **"How people treat it" category of this platform,** users are allowed to input what treatments they have tried. When PatientsLikeMe data is compared to Medicare data, the PatientsLikeMe appears limited. In an analysis occurring from 2010 – 2014, Shrestha et al. collated data from commercial, Medicare, and Medi-Cal treatment regimens of AD. Treatment according to Medicare includes topical corticosteroids (60.3%), systemic corticosteroids (39.6%), no treatment (26.2%), systemic immunosuppressant (1.1%), topical calcineurin inhibitor (1.1%), and phototherapy (1.1%), [17]. This data, in addition to commercial and Medi-Cal reports, are summarized in Table 4. Alternatively, the treatment data reported on PatientsLikeMe is comprised of just 28 respondents (6.8% of AD respondents). Of these, 60.7% (17/28) reported using topical steroids, a value on-par with that of current literature. However, systemic steroids, tacrolimus, dupilumab, and antibiotics each only had one user report these therapies. The latter observation highlights the poor sample size of this section of the AD patient profile. That said, this portion of the data is of little use to practitioners. It should be noted that **PatientsLikeMe does not have a "No treatment"** option. Accordingly, healthcare providers should use caution when extrapolating data from self-reported online medical communities.

Treatment of AD first involves the elimination of exacerbating compounds and conditions. Other therapies include restoration of skin hydration, proper bathing habits, and temporary steroid application. While PatientsLikeMe allows users to report treatment usage, it does neither address standard of care for AD, nor the multitude of other therapies available including avoidance of eliciting compounds, barrier emollients, moisturizers, calcineurin inhibitors, antihistamines, cyclosporine, antimetabolites, or other immunosuppressive drugs [18].

Lastly, health care providers must become increasingly aware of patient confidentiality when interacting with patients. Many online communities, including PatientsLikeMe, are not anonymous and sensitive information is often shared in these communities. With this in mind, due diligence is necessary by providers when discussing shared clinical vignettes. This is done by depersonalizing the information and concealing the source of the information [8]. While seemingly apparent, there have been major breaches in Health Insurance Portability and Accountability Act (HIPAA), [19].

Limitations
There are a multitude of communities and tools that allow users to record and track their condition. Although PatientsLikeMe is an excellent database to record a multitude of diseases and provide a platform for patients to connect with one another, clinical accuracy and reliability of self-reported data must be considered.

According to Ventola et al., information reported through these communities may lack quality and reliability. Claims and medical information posted by users is often unreferenced, incomplete, or misinformed [8]. Current evidence-based medicine (EBM) guidelines refer to systematic reviews and critically-appraised topics as high-level evidence. Alternatively, online communities are comprised primarily of personal anecdotes and experiences, which are considered low levels of evidence, according to current guidelines [20].

Online community demographics often do not represent populations with a specific disease. Sadah et al. reports that 75% of web-based health-related social media users are white Caucasian women [15].

This data cannot be stratified through PatientsLikeMe because it is not included in the database available to the public, even though patients are still encouraged to report their race on their profile. Furthermore, the individuals sharing their information must also be considered. According to one study, many online communities adhere to the "1% rule." This observation indicates that 1% of users generate the majority of original content and 9% may contribute their information occasionally. However, 90% of users will simply observe without contributions [21]. Furthermore, the PatientsLikeMe platform does not require patients to complete their profile and may opt to fill select sections only. While this feature allows for greater autonomy, consistencies and validation of data becomes more difficult.

Provided PatientsLikeMe is an online community requiring internet access, there is a portion of the population that does not have regular access. In fact, Carroll et al. describes the "digital divide" and a direct correlation between higher socioeconomic status and increased access to a computer/internet. Conversely, lower income individuals have decreased access to such resources [22]. This observation favors online communities comprised of individuals with greater socioeconomic standing. Fundamentally, this decreases representation and disease characterization of poor populations.

Conclusion
Patient-oriented medical communities serve as a useful resource for those with various conditions. The opportunity to share "your story" and discuss conditions affords patient therapy in addition to their medical regimen. Clinical applications of community driven health data are still uncertain.

Table 4: *Comparison of PatientsLikeMe Reported Treatments vs. Commercial, Medicare, and Medi-Cal. [12]*

	PatientsLikeMe (%)	Commercial (%)	Medicare (%)	Medi-Cal (%)
Topical Corticosteroid	60.3	60.9	60.3	71.9
Systemic corticosteroid	3.57	34.9	39.6	21.0
Topical calcineurin inhibitor	3.57	4.4	1.1	1.1
Home remedies	25%	Not reported	Not reported	Not reported
Systemic immunosuppressant	Not reported	1.1	1.3	0.9
Phototherapy	Not reported	1.0	1.1	0.4
No Treatment	Not reported	25.6	26.2	23.5

Data derived from these communities provides broad generalizations, unverifiable accuracy, and uncertain relevance with regard to clinical decision making. While medical communities are abundant with data and patient excerpts, there is minimal large group census information readily available. In other words, this data has yet to translate into standardized patient care. However, as patient-oriented medical communities continue to expand and grow, clinical significance may become more apparent.

References

1. Berke R, Singh A, Guralnick M. Atopic dermatitis: an overview. *Am Fam Physician.* 2012;86(1):35-42. [PMID: 22962911].
2. Lim HW, Collins SAB, Resneck JSJ, et al. The burden of skin disease in the United States. *J Am Acad Dermatol.* 2017;76(5):958-972.e2. [PMID: 28259441].
3. Boguniewicz M, Leung DY. Atopic Dermatitis: A Disease of Altered Skin Barrier and Immune Dysregulation. *Immunol Rev.* 2011;242(1):233-246. [PMID: 21682749].
4. Rundle CW, Bergman D, Goldenberg A, Jacob SE. Contact dermatitis considerations in atopic dermatitis. *Clin Dermatol.* 2017;35(4):367-374. [PMID: 29923849].
5. Thomsen SF. Atopic Dermatitis: Natural History, Diagnosis, and Treatment. *ISRN Allergy.* 2014;2014:354250. [PMID: 25006501].
6. Thyssen JP, Skov L, Hamann CR, Gislason GH, Egeberg A. Assessment of major comorbidities in adults with atopic dermatitis using the Charlson comorbidity index. *J Am Acad Dermatol.* 76(6):1088-1092.e1. [PMID: 28392292].
7. Cheng C-M, Hsu J-W, Huang K-L, et al. Risk of developing major depressive disorder and anxiety disorders among adolescents and adults with atopic dermatitis: A nationwide longitudinal study. *J Affect Disord.* 2015;178:60-65. [PMID: 28890845].
8. Ventola CL. Social Media and Health Care Professionals: Benefits, Risks, and Best Practices. *Pharm Ther.* 2014;39(7):491-520. [PMID: 25083128].
9. Wicks P, Massagli M, Frost J, et al. Sharing Health Data for Better Outcomes on PatientsLikeMe. Eysenbach G, ed. *J Med Internet Res.* 2010;12(2):e19. [PMID: 20542858].
10. Odhiambo JA, Williams HC, Clayton TO, Robertson CF, Asher MI. Global variations in prevalence of eczema symptoms in children from ISAAC Phase Three. *J Allergy Clin Immunol.* 124(6):1251-1258.e23. [PMID: 20004783].
11. Schultz Larsen F, Diepgen T, Svensson A. The occurrence of atopic dermatitis in north Europe: an international questionnaire study. *J Am Acad Dermatol.* 1996;34(5 Pt 1):760-764. [PMID: 8632070].
12. Shaw TE, Currie GP, Koudelka CW, Simpson EL. Eczema Prevalence in the United States: Data from the 2003 National Survey of Children's Health. *J Invest Dermatol.* 131(1):67-73. [PMID: 20739951].
13. Silverberg JI, Hanifin J, Simpson EL. Climatic Factors Are Associated with Childhood Eczema Prevalence in the United States. *J Invest Dermatol.* 133(7):1752-1759. [PMID: 23334343].
14. Tay Y‐K., Kong K‐H., Khoo L., Goh C‐L., Giam Y‐C. The prevalence and descriptive epidemiology of atopic dermatitis in Singapore school children. *Br J Dermatol.* 2003;146(1):101-106. [PMID: 11841373].
15. Sadah SA, Shahbazi M, Wiley MT, Hristidis V. A Study of the Demographics of Web-Based Health-Related Social Media Users. Eysenbach G, ed. *J Med Internet Res.* 2015;17(8):e194. [PMID: 26250986].
16. Mina S, Jabeen M, Singh S, Verma R. Gender Differences in Depression and Anxiety Among Atopic Dermatitis Patients. *Indian J Dermatol.* 2015;60(2):211-211. [PMID: 25814727].
17. Shrestha S, Miao R, Wang L, Chao J, Yuce H, Wei W. Burden of Atopic Dermatitis in the United States: Analysis of Healthcare Claims Data in the Commercial, Medicare, and Medi-Cal Databases. *Adv Ther.* 2017;34(8):1989-2006. [PMID: 28707285].
18. Lee JH, Son SW, Cho SH. A Comprehensive Review of the Treatment of Atopic Eczema. *Allergy Asthma Immunol Res.* 2016;8(3):181-190. [PMID: 26922927].
19. O'Hara B, Fox BI, Donahue B. Social media in pharmacy: heeding its call, leveraging its power. *J Am Pharm Assoc JAPhA.* 2013;53(6):561-564. [PMID: 24185437].
20. Burns PB, Rohrich RJ, Chung KC. The Levels of Evidence and their role in Evidence-Based Medicine. *Plast Reconstr Surg.* 2011;128(1):305-310. [PMID: 21701348].
21. Fox S, Purcell K. PIP_Chronic_Disease_with_topline.pdf. http://www.pewinternet.org/files/old-media/Files/Reports/2010/PIP_Chronic_Disease_with_topline.pdf. Accessed on January 18, 2018.
22. Carroll AE, Rivara FP, Ebel B, Zimmerman FJ, Christakis DA. Household computer and Internet access: The digital divide in a pediatric clinic population. *AMIA Annu Symp Proc.* 2005;2005:111-115. [PMID: 16779012].