



Original Research

A feasibility study of the burden of disease of atopic dermatitis using a smartphone research application, *myEczema*Sheevam Shah MD^a, Jacqueline M. Kemp MD, MS^{b,c}, Joseph C. Kvedar MD^{c,d}, Lia E. Gracey MD, PhD^{a,*}^a Baylor Scott & White Health, Department of Dermatology, Lakeway, TX, United States^b Brigham and Women's Hospital, Department of Dermatology, Boston, MA, United States^c Harvard Medical School, Boston, MA, United States^d Connected Health, Partners HealthCare, Boston, MA, United States and Harvard Medical School, Boston, MA, United States

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ABSTRACT

Background: Our understanding of chronic diseases, such as atopic dermatitis (AD), could benefit from the ability to rapidly collect patient-reported, longitudinal data from a large population.**Objective:** This study aimed to determine whether a smartphone app can be used to collect demographic and longitudinal symptom data and recognize prescribing patterns and affordability of medications to study the burden of AD.**Methods:** We collected data using the *myEczema* smartphone app between July 2017 and April 2018. The data were de-identified and analyzed.**Results:** A total of 519 users (94.2%) completed the initial demographic survey. The majority of users were female (n = 387; 70.2%) and Caucasian (n = 358; 65.0%). A total of 335 users (60.8%) had at least a university degree and were employed (n = 348; 63.1%). A total of 189 users (29.2%) reported difficulty affording their medications, and 363 users (65.9%) took advantage of the itch score recording feature. Finally, 184 users (33.4%) logged their treatments, with the highest number of users (65.2%) listing topical steroids as one of their treatments.**Limitations:** The operating platform was limited to iPhones, and the results were subject to reporting bias.**Conclusion:** A smartphone-based research app can be used to rapidly collect patient-reported data to study the burden of AD and to highlight the prescribing patterns and affordability of medications.© 2020 Published by Elsevier Inc. on behalf of Women's Dermatologic Society. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Introduction

The ubiquity of smartphones is well established, with an estimated 223 million smartphone users in the United States (Statista, 2018). The average U.S. consumer spends 5 hours per day on a mobile device, and 92% of this time is spent using applications (apps), including social media, video streaming, and music (Flurry Analytics, 2017). Given its convenience, the smartphone has become a powerful tool to transform the way data are collected and potentially harnessed for clinical research. Advantages include the removal of geographic barriers for people to participate in clinical research and an ability for frequent, real-time data collection.

In 2015, Apple, Inc. (Cupertino, CA) released an open-source framework for building smartphone apps for clinical research data collection, dubbed ResearchKit (Apple, 2018). Prior pilot studies

have demonstrated an ability to rapidly recruit a large population from across the United States with varying success in collecting cross-sectional and longitudinal data for a variety of conditions (Chan et al., 2017; Crouthamel et al., 2018; Dorsey et al., 2017; Webster et al., 2017). App-based research efforts especially have promise in addressing research gaps for chronic skin conditions that would benefit from frequent symptom tracking and further demographic insights.

Approximately 31.6 million individuals in the United States have some form of eczema (Hanifin and Reed, 2007). The annual economic burden of eczema is estimated at \$5.3 billion (National Eczema Association, 2018). For patients and practitioners alike, eczema can be a frustrating, consuming condition that affects quality of life for patients and their families.

Herein, we present our efforts to demonstrate the feasibility of using a smartphone app, *myEczema*, to collect patient-reported outcomes data to study the burden of disease of atopic dermatitis (AD), a type of eczema. We specifically aimed to collect

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demographic data, highlight the prescribing patterns and affordability of medications in the United States, and collect longitudinal symptom data. The design of the myEczema smartphone app was a physician-led effort, created in consultation with dermatologists, eczema researchers, and patients with eczema and their families (Gracey et al., 2018). At the time of the study, myEczema was the only eczema app that collected user-entered data and securely stored the data in a de-identified manner to be used for institutional review board–approved research.

Methods

myEczema was listed as a free-download app in the iTunes store, with data collection occurring from July 1, 2017 through April 2, 2018. Once users downloaded the app, they were asked to consent to its terms and conditions in order to participate. The user was then presented with an initial onboarding survey for demographic information. All questions were optional, and the user could skip any questions if desired. After completion of the demographic survey, the user was asked to enter an itch score. Push notifications were sent to users once a week to enter an itch score and once every 6 weeks to take a treatment survey. Completion of itch scores and surveys was optional. The collected data-points were de-identified, assigned to a random patient identification number, and analyzed in aggregate using ArcGIS and Excel (Microsoft Corp., Redmond, WA). There were no medical interventions, human interaction with users, or external incentives throughout the study. This study was approved by the Partners Healthcare institutional review board.

Results

Between July 1, 2017 and April 2, 2018, 551 people downloaded myEczema. Thirty-two users did not fully respond to the initial survey and were removed from our analyses. Overall user demographics are displayed in Table 1. A total of 387 patients (70.2%) were female and 358 (65.0%) identified as Caucasian. In addition, 405 users (73.5%) were adult patients with eczema and 146 (26.5%) were caregivers of children with eczema. A total of 335 users (60.8%) had at least a university degree, and 348 (63.1%) were employed while using myEczema. A total of 305 users (58.8%) had been diagnosed with AD specifically by a dermatologist.

A total of 189 users across the United States (29.2%) reported difficulty affording their medications (Fig. 1A). Of these users, 43 (44.3%) resided in the Midwest, 27 (19.9%) in the Northeast, 28 (28.6%) in the West, and 61 (38.9%) in the South (U.S. Census Bureau, 2019). In addition, 363 users (65.9%) took advantage of the itch score recording feature of myEczema. Of those, 83 users (22.9%) logged at least four itch scores and interacted with the app for an average of 1.2 months (Table 1). Users were sent push notifications to log an itch score once a week.

Users were also prompted to update their treatment lists and treatment adherence every 6 weeks. A total of 184 users (33.4%) logged their treatments and answered the treatment adherence question. The majority of users (n = 120; 65.2%) listed topical steroids as one of their treatments (Fig. 2). Nonprescription topical medications were the most popular, with most commonly CeraVe (n = 60; 32.6%), Vaseline (n = 55; 29.9%), and Aveeno (n = 56; 30.4%). Topical oils, such as olive, mineral, and coconut oil, were also popular (n = 47; 25.5%). Of the prescription topical therapies, hydrocortisone (n = 48; 26.1%) and triamcinolone (n = 48; 26.1%) were the most commonly used. Fifty-five users (29.9%) logged systemic treatments, including mycophenolate mofetil, cyclosporine, dupilumab, methotrexate, phototherapy, and prednisone. Not surprisingly, systemic therapies for AD were more highly prescribed

Table 1
User demographics and interactions.

Variable	n (%)
Type of participant	
Adult patient with eczema	405 (73.5)
Caregiver of a child with eczema	146 (26.5)
Patient sex	
Male	163 (29.6)
Female	387 (70.2)
Other	1 (0.2)
Age of patient with eczema (years)	
0–5	105 (19.4)
6–17	80 (14.8)
18–30	183 (33.9)
31–49	128 (23.7)
50+	44 (8.1)
Race/ethnicity	
Caucasian/white	358 (65.0)
African American/black	33 (6.0)
Hispanic	32 (5.8)
Asian	127 (23.0)
Native American	1 (0.2)
Highest educational level	
Postgraduate degree	110 (20.0)
University degree	225 (40.8)
Trade school/some college	107 (19.4)
High school or less	89 (16.2)
Other	20 (3.6)
Employment status	
Employed full-time	264 (47.9)
Employed part-time	84 (15.2)
Student	95 (17.2)
Unemployed	49 (8.9)
Other	59 (10.7)
Physician making the diagnosis of eczema	
Dermatologist	305 (58.8)
Family practice	106 (20.4)
Pediatrician	89 (17.1)
Other	19 (3.7)
Known diagnosis of atopic dermatitis	
Yes	338 (65.1)
No	33 (6.4)
Unsure	148 (28.5)
Years since diagnosis	
<1	182 (33.0)
1–10	228 (41.4)
11+	141 (25.6)
Difficulty affording medications	
Yes	189 (29.2)
No	409 (63.1)
Number of itch scores logged	
≤3	280 (77.1)
4–9	59 (16.3)
≥10	24 (6.6)

around urban areas and academic centers, presumably where there are often more resources for laboratory monitoring and access to physicians (Fig. 1B).

Users of the app reported high treatment adherence, with only 6% of patients who logged treatments indicating that they were rarely or never adherent. Nine users continuously logged adherence answers and engaged with the app for at least 18 weeks. These users tended to be Caucasian and have a higher level of education, with at least a university degree.

Discussion

We conducted a prospective observational study assessing the feasibility of using a smartphone app as a data collection tool for AD. Our platform allowed us to collect demographic and symptom data, while also highlighting the prescribing patterns and affordability of medications in the United States. We envision these data being useful, not only for health care professionals but also for driving future insurance coverage and health policy.

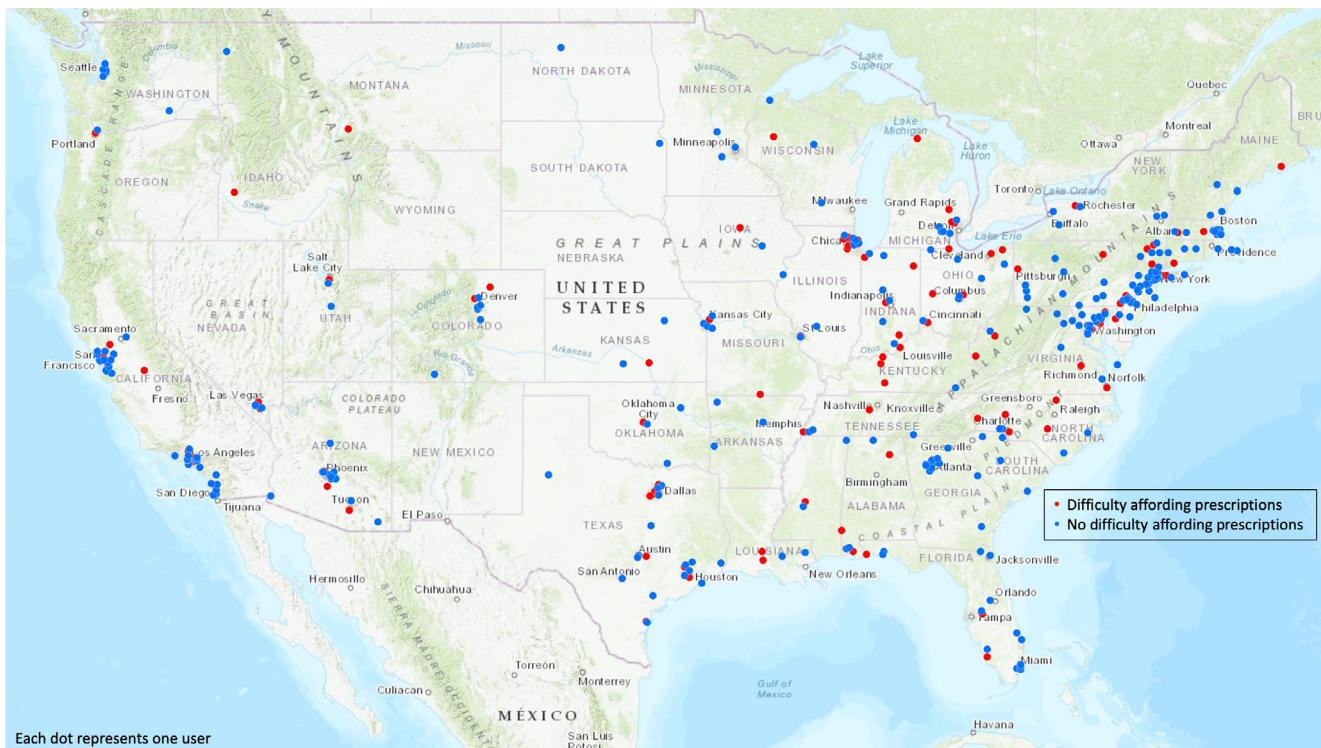


Fig. 1. (A) U.S. distribution of users having difficulty affording their prescriptions and (B) U.S. regions where patients reported being on systemic medications for eczema.



Fig. 1 (continued)

Limitations

Our study had multiple limitations, including patient selection bias, reporting bias, and the operating platform. Current standards

for assessing the impact on data validity are not well defined for smartphone research apps and were not investigated in detail herein as a feasibility study. Only 6% of patients reported that they were rarely or never adherent with their treatments; it is feasible

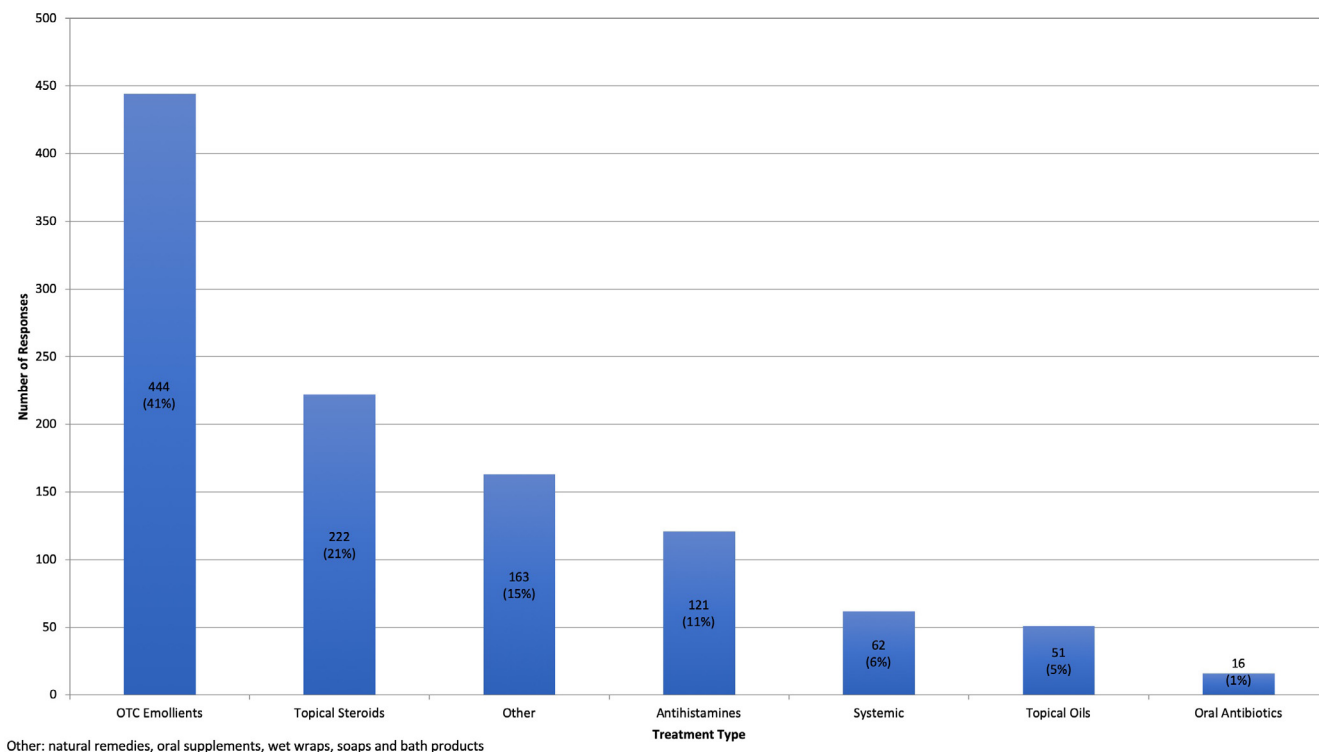


Fig. 2. Distribution of patient-reported atopic dermatitis emollients and medications.

that less adherent patients are not interested in downloading an app for AD management. The myEczema app was only available on iPhones, which potentially skewed our data toward a more affluent and educated population. This may have contributed to our findings that only 189 patients (29.2%) had difficulty affording their medications. Users who interacted with the app the most tended to be female, Caucasian, and have a university degree. These limitations may confine the generalizability of our findings but nonetheless highlight important features of users who could be engaged as smartphones continue to become integrated in health care.

User engagement

Unlike clinical research, which can take years to perform, app-based research tends to have a much shorter timeline. This is likely due to the rapid loss of interest in not only research-based apps, but most apps in general. This loss of interest translates to low retention rates, which is cited as a limitation in multiple app-based studies (Chan et al., 2017; Dorsey et al., 2017). Research-oriented apps are difficult to engage with long term, especially compared with social media apps, which provide users with rich and interactive media.

Although users were not required to complete the initial onboarding survey, we had a 94.2% (n = 519) response rate. Of the users who did not respond to the initial survey, the majority did not reside in the United States. A prior ResearchKit-based study reported a success rate of 85.2% in getting users to respond to at least one survey in their respective apps, but several studies noted a high attrition rate with only 4% to 30% of users still interacting after 1 month (Chan et al., 2017; Dorsey et al., 2017). Keeping a user engaged with our app was difficult, with similar retention rates as previous studies (Crouthamel et al., 2018; Dorsey et al., 2017). Future versions of the app could ideally include a game feature, incentive structure, or more personalized eczema manage-

ment tools to further improve the length of user engagement with the research app.

Overall, we believe the optimal usage of a smartphone app for a dermatologic condition would be for an individual or family motivated to use the tool to improve their understanding of which factors affect the expression of their disease. When patients and their family members want to engage with their care, the use of a smartphone app could make a significant impact.

Conclusion

Our work demonstrated that a smartphone app can be used to collect demographic, symptom, and treatment data to study the burden of disease of AD. We hope that this foundation leads to future longitudinal data collection to learn how to improve AD management for a reduced number of flares and ultimately a reduction in the national economic burden of AD.

Conflicts of interests

Dr. Lia Gracey is an associate editor for tele dermatology at the *International Journal of Women's Dermatology*. She will recuse herself from any editing processes for this article. All other authors have no conflicts of interest to declare.

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Study Approval

The author(s) confirm that any aspect of the work covered in this manuscript that has involved human patients has been conducted with the ethical approval of all relevant bodies.

References

- Apple. ResearchKit [Internet]. 2018 [cited 2018 August 10]. Available at: <https://developer.apple.com/researchkit/>.
- Chan YFY, Wang P, Rogers L, Tignor N, Zweig M, Hershman SG, et al. The Asthma Mobile Health Study, a large-scale clinical observational study using ResearchKit. *Nat Biotechnol* 2017;35(4):354–62.
- Crouthamel M, Quattrocchi E, Watts S, Wang S, Berry P, Garcia-Gancedo L, et al. Using a ResearchKit smartphone app to collect rheumatoid arthritis symptoms from real-world participants: feasibility study. *JMIR Mhealth Uhealth* 2018;6(9):e177.
- Dorsey ER, Chan YF, McConnell MV, Shaw SY, Trister AD, Friend SH. The use of smartphones for health research. *Acad Med* 2017;92(2):157–60.
- Flurry Analytics. U.S. consumers time-spent on mobile crosses 5 hours a day [Internet]. 2017 [cited 2018 August 10]. Available at: <http://flurrymobile.tumblr.com/post/157921590345/us-consumers-time-spent-on-mobile-crosses-5>.
- Gracey L, Zan S, Gracz J, Miner JJ, Moreau JF, Sperber J, et al. Use of user-centered design to create a smartphone application for patient-reported outcomes in atopic dermatitis. *NPJ Digit Med* 2018;1:33.
- Hanifin J, Reed M. A population-based survey of eczema prevalence in the United States. *Dermatitis* 2007;18(2):82–91.
- National Eczema Association. Eczema facts [Internet]. 2018 [cited 2018 August 10]. Available at: https://nationaleczema.org/research/eczema-facts/#_ftn11.
- Statista. Number of smartphone users in the United States from 2010 to 2022 (in millions) [Internet]. 2018 [cited 2018 August 15, 2018]. Available at: <https://www.statista.com/statistics/201182/forecast-of-smartphone-users-in-the-us/>.
- U.S. Census Bureau. Census regions and divisions of the United States [Internet]. 2019 [cited 2019 January 20]. Available at: https://www2.census.gov/geo/pdfs/maps-data/maps/reference/us_regdiv.pdf.
- Webster DE, Suver C, Doerr M, Mounts E, Domenico L, Petrie T, et al. The Mole Mapper Study, mobile phone skin imaging and melanoma risk data collected using ResearchKit. *Sci Data* 2017;4:170005.