



Characterization of online support group resources for patients with dermatologic conditions

Trisha Kaundinya¹ · Salma El-Behaedi² · Sara Bilimoria¹ · Jennifer N. Choi²

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Abstract

Dermatologic conditions can have significant quality of life effects on patients. The internet is a first-line accessible resource for patients to seek support and community in managing dermatologic diagnoses. The accessibility and content of online support resources for patients with dermatologic conditions is unclear so we sought to characterize these resources. We conducted online searches utilizing incognito Google, Yahoo, and Bing search engines and identified a total of 36 support group resources. 9 links were for single dermatology support groups and 27 links were for databases of support groups for different dermatologic conditions. We tallied number totals and percentages of online support resources and found wide variability of material in terms of the readability of the group websites, as well as content, medium, and hosts of the groups. Furthermore, we observed an imbalance in representation of resources for certain dermatologic conditions as opposed to others, further highlighting the strong need for the creation of easy-to-access support groups for patients across the spectrum of dermatological disease.

Keywords Support group · Online · Dermatology · Quality of life

Introduction

Dermatologic diseases can have significant psychosocial effects through which they alter the thought processes, beliefs, and relationships of patients [1]. This is due not only to the nature and pathophysiology of dermatological diseases, but also the visibility and longitudinal nature and societal stigmas surrounding these conditions [2, 3]. These alterations can modulate patients' levels of anxiety and depression, and beliefs about the severity of their disease and ability to cope with it, which altogether modulate quality of life [4, 5]. Research indicates that patients with most dermatological diseases experience negative changes to their quality of life due to their condition [6–10].

Support groups have been posited as a beneficial resource for patients with chronic dermatologic conditions [11].

While the mechanisms of these effects still require investigation, analogous groups for chronic disease have shown to improve functional status, increase self-perceived coping, and improve quality of life [12, 13]. Given the stigma that is unfortunately carried by dermatological conditions and that patients may face from colleagues, friends and family, patients may not always feel comfortable reaching out to their social supports or providers throughout their disease course. They may often use sources on the internet for support and advice prior to reaching out to a specialist.

The first-line resource for patients to access medical information and support is often the internet [14]. In light of the Covid-19 pandemic, the internet has increasingly been utilized as a medical resource [15]. Furthermore, online resources serve as the initial and sometimes primary means of medical guidance available to some patient populations [16]. Thus, assessing the content and readability of such resources is imperative as it serves to guide the creation of better educational and support materials for a wide population of patients.

The content and understandability of online support group resources for patients with dermatologic conditions who use the internet is currently unknown and thus we sought to quantitatively characterize this.

✉ Jennifer N. Choi
jennifer.choi@northwestern.edu

¹ Northwestern University Feinberg School of Medicine, Chicago, IL 60611, USA

² Department of Dermatology, Northwestern University Feinberg School of Medicine, NMH/Arkes Family Pavilion Suite 1600, 676 N Saint Clair, Chicago, IL 60611, USA

Methods

This study was exempt from institutional review board (IRB) approval because it only included published online links on the internet.

Online web search

The Google, Yahoo, and Bing Search engines were utilized for the web search with the search terms “Dermatology support group” on March 21, 2021 using a private incognito window. The top 50 search results of each search engine were exported for review, for a total of 150 results.

Web links were included if they met any of the following criteria: 1. Links which feature support groups for just one dermatologic condition, or 2. Links which are databases of support group links for multiple dermatologic conditions. Both physician-authored and non-physician authored content was included. Both university-hosted and non-university-hosted links were included.

Web links were excluded if they met the following criteria: (1) Academic primary literature. (2) Press releases. (3) Audiovisual patient support. (4) Patient education overviews. (5) Not dermatologic conditions. (6) Healthcare provider profile pages. (7) Not in English.

Data extraction

Two authors (TK, SB) independently screened all 150 results against inclusion and exclusion criteria. Inconsistencies were resolved by consensus discussion. The search process is summarized in Fig. 1.

Included web links from each database were assessed for their coverage of support group resources. The number of support groups and types of dermatologic conditions listed on the websites was collected, in addition to contact information for the groups, location and host of support group, and format of support group. All included web links for support groups were assessed to obtain an understandability score and actionability score with the Patient Education Materials Assessment Tool (PEMAT), a tool validated by the Agency for Healthcare Research and Quality [17]. These scores, from 0 to 100 for each site, are intended for relative comparison of ease of comprehension and ability to act on the educational content, with a higher score indicating higher level of ease and higher actionability.

Analysis was primarily descriptive, with tallied total numbers and percentages of website content and metrics collected as above.

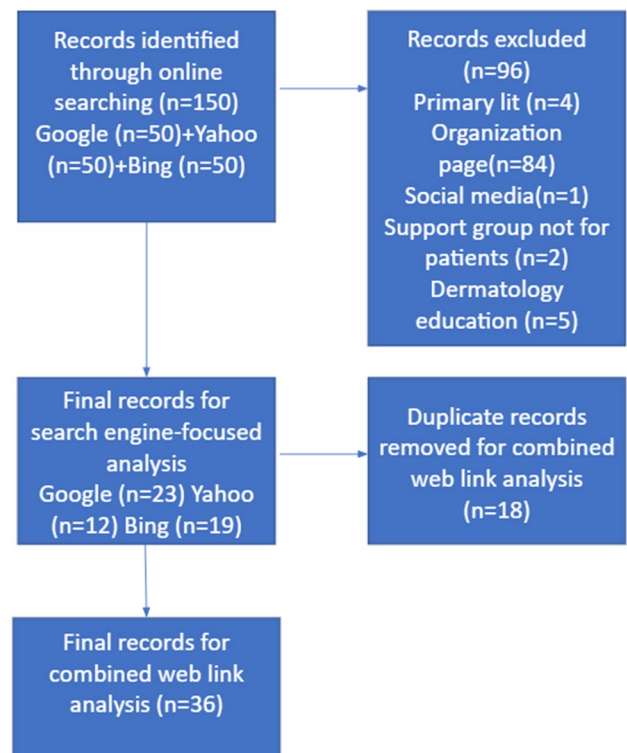


Fig. 1 Search strategy for support groups

Results

After screening the top 50 results for the Google, Yahoo, and Bing searches, there were a total of 54 included results. Three websites were present in Google, Yahoo, and Bing searches, 3 websites were duplicate in both Google and Bing searches, and 3 websites were duplicates in both Yahoo and Bing searches. Thus, after complete deduplication, there were 36 website links. Of the 36 websites, 9 (25.0%) directed readers to a single support group and 27 websites (75.0%) were databases of support groups for different dermatologic conditions.

In the Google search results, there were 17 (73.9%) links to databases and 6 (26.1%) links to individual support groups (Table 1). Groups were primarily based in the USA (65.2%) and hosted by nonacademic centers (82.6%). 56.5% of websites provided a contact email, 52.2% provided a contact phone number, and 65.2% provided a link to social media for the support group. The mean PEMAT understandability score was 74.0 and mean actionability score was 35.0.

In the Yahoo search results, there were 10 (83.3%) links to databases and 2 (16.7%) links to individual support groups. Groups were primarily based in the USA (66.7%) and hosted by nonacademic centers (100%). 58.3% of websites provided a contact email, 58.3% provided a contact phone number,

Table 1 Google, yahoo, and bing dermatologic support group website results

	Google search results (<i>n</i> = 23)	Yahoo search results (<i>n</i> = 12)	Bing search results (<i>n</i> = 19)
Metric	Number (percentage)		
Databases	17(73.9)	10 (83.3)	16 (84.2)
Single links	6(26.1)	2 (16.7)	3 (15.8)
Link hosted by a nonacademic center	19(82.6)	12 (100)	18 (94.7)
Link hosted by an academic center	4(17.4)	0 (0)	1 (5.3)
Location of support groups described in website	15 (65.2) US, 2 (8.7) UK, 2 (8.7) Canada, 4 (17.4) unspecified	8 (66.7) US, 1(8.3) UK, 3(25.0) Canada	10 (52.6) US, 3 (10.5) unspecified international, 3 (15.8) UK, 3 (15.8) Canada
State (if provided)	2 (8.7) NC, 1(4.3) MN, 1 (4.3) IN, 2 (8.7) IL, 1 (4.3) NJ, 1 (4.3) GA, 1 (4.3)PA	1 (8.3) NJ, 1 (8.3) PA	1 (5.3) CA, 1 (5.3)GA, 1 (5.3)MN, 1(5.3)NC, 1(5.3)NJ, 2(10.6)PA
Format of support groups	3 (50) virtual, 3(50) hybrid	1 (50), 1 (50) unspecified	1(33.3) hybrid, 2 (66.7) unspecified
Main website provided contact email	13 (56.5)	7 (58.3)	10 (52.6)
Main website provided contact phone number	12 (52.2)	7 (58.3)	12 (63.2)
Main website provided social media link	15 (65.2)	9 (75)	15 (78.9)
Description of each support group	9 (52.9)	6 (60)	10 (62.5)
Caregiver support groups available	2 (8.7)	1 (8.3)	3 (15.8)
PEMAT understandability	74.0	81.5	79.4
PEMAT actionability	35.0	40.3	48.3

Descriptive counts and percentages of location, format, contact information, and understandability of web links for support groups for dermatologic conditions on Yahoo, Bing, and Google.

PEMAT Patient Education Materials Assessment Tool, US United States, UK United Kingdom, NC North Carolina, MN Minnesota, IN Indiana, IL Illinois, NJ New Jersey, GA Georgia, PA Pennsylvania, CA California

and 75.0% provided a link to social media for the support group. The mean PEMAT understandability score was 81.5 and mean actionability score was 40.3.

In the Bing search results, there were 16 (84.2%) links to databases and 3 (15.8%) links to individual support groups. Groups were primarily based in the USA (52.6%) and hosted by nonacademic centers (94.7%). 52.6% of websites provided a contact email, 63.2% provided a contact phone number, and 78.9% provided a link to social media for the support group. The mean PEMAT understandability score was 79.4 and mean actionability score was 48.3

Single links

Of the 9 unique websites which linked to one single support group, 3 websites (33.3%) were for psoriasis, 1 (11.1%) was for dermatologic care after organ transplantation, 1 (11.1%) was for hidradenitis suppurativa, 1 (11.1%) was for pityriasis rubra, and 3 (33.3%) were not specified. Five (55.5%) were groups based in the USA, 1 (11.1%) was international, and 3 (33.3%) did not provide location. Six (66.7%) websites detailed groups hosted by non-academic

institutions. Five (55.5%) websites listed a contact email, 4 (44.4%) listed a phone number, and 4 (44.4%) shared a social media link. The mean PEMAT understandability score was 66.6, and the mean actionability score was 32.4.

Databases

Of the 27 unique support group databases identified, the average number of dermatologic conditions included was 13.8 (Table 2). 20 (74%) databases contained information regarding at least one autoimmune or inflammatory cutaneous condition. Of the databases with links to support groups to autoimmune conditions, there were the greatest number of support group links for psoriasis, vitiligo, and alopecia areata. Of the databases which had links to support groups to inflammatory conditions, there were the greatest number of support group links for acne, atopic dermatitis, and psoriasis. Of the databases which had links to support groups for inflammatory conditions, only one discussed hidradenitis suppurativa.

Table 2 Dermatologic support group database search results

Metric	Number (percent)
Average number of dermatologic diseases with support groups in each database	13.8
Support group links for Rheumatologic and Autoimmune dermatologic diseases	20 (74)
Support group links provided for neoplastic dermatologic diseases	17 (62.9)
Support group links provided for inflammatory dermatologic diseases	20 (74)
Support group links provided for psychocutaneous dermatologic diseases	0 (0)
Support group links provided for infectious and bacterial dermatologic diseases	6 (22.2)

Descriptive counts and percentages of support groups for different dermatologic diseases on online databases of online support groups.

Of all databases, 17 (62.9%) had links to support groups for neoplastic cutaneous conditions, with the most frequent condition being melanoma. There were no links to support groups for non-melanoma skin cancers (NMSC). Six (22.2%) of the databases contained information on infectious cutaneous sequelae including shingles, herpes, and sexually transmitted infections (STIs). None of the website databases had groups pertaining to primary psychocutaneous conditions, such as trichotillomania, delusions of parasitosis, factitious dermatitis, or dysmorphophobia.

Discussion

Support groups have shown to be an important and beneficial non-pharmacologic intervention for patients with an array of systemic chronic diseases [18–20]. When patients need support resources, access and convenience are a priority [21]. Virtual support resources, with their high accessibility and convenience, are thus a tool with high utilization by patients. [22–24]

Specifically in dermatology literature, virtual support groups have shown to be beneficial for improving quality of life as well as disease severity. Several studies have looked at the impact of support group interventions in a variety of dermatologic diseases ranging from systemic lupus erythematosus (SLE), to hidradenitis suppurativa, to malignant melanoma [25–27]. Such studies have found that the benefit from support group interventions may span not only an improvement in disease status, but also the psychosocial landscape for many patients, allowing for a heightened sense of community, decreased feelings of isolation, and a focus on more effective emotion-focused coping strategies.

Our study is the first to our knowledge to review and characterize the content of links to online support groups for dermatologic conditions. In our study, altogether with Google, Yahoo, and Bing, 36 unique support group links were identified. A significant majority of resources were hosted on nonacademic centers and consisted of a database of support group links. The format of support groups were a

mix of hybrid, in person, and virtual. Approximately half of links provided a contact phone number and approximately half of links provided a contact email. Under 20% of links contained information on caregiver support, and average PEMAT understandability scores ranged from 74 to 81 between the search engines. While scores are typically used to compare sources to one another, the maximum PEMAT score is a 100 indicating maximal readability. Thus, there is room to improve how understandable these web support group resources are to patients.

Twenty-seven unique dermatologic support group databases were identified, and it is evident that there is a sizeable imbalance of representation of dermatologic conditions. For example, although a significant proportion of databases contained support resources on autoimmune or inflammatory conditions in dermatology, the focus of support group links tended to be on the same few conditions that were repeatedly represented, such as atopic dermatitis. Of note, dermatologic conditions with a higher incidence in traditionally marginalized patient populations had the greatest deficit in representation in online databases. As one example, hidradenitis suppurativa is a condition that has prevalence rates highest in the African–American population [28], yet only a single database had information pertaining to the management of this condition. Furthermore, the psychiatric population in medicine is one that faces several unique barriers to healthcare access [29], yet none of the databases contained information on primary psychocutaneous conditions. Given the self and society-mediated barriers that patients with psychiatric co-morbidities of their dermatologic diseases may face with seeking psychiatric care, the presence of readily available online support resources for this group is perhaps of greatest need [30]. Although neoplastic conditions were represented in over half of online databases, there tended to a focus on melanoma versus NMSCs despite the greater incidence of NMSCs in the general population.

There is great variability in content and coverage of online support group resources for patients with dermatologic conditions, and thus patients may not always be able to join groups from the information that they seek and find online. Access to support groups is a barrier that has been cited in the literature [31, 32] and virtual group resources, while having the potential to mitigate the access barrier,

do not always actionably do so [33]. Further research is necessary to evaluate additional sources of support group materials for patients with dermatologic conditions. The characterization of support group resources available to patients can inform clinicians and support group organizations to better reach and recruit patients with an array of dermatologic conditions. If the content of the links to support groups include more conditions and are easy to understand and act on, such as through provided contact numbers and email information, recruitment and longitudinal involvement can be optimized and patients can maximize benefits of the groups.

There were a few limitations in this study. Analysis was limited to the top 50 results in each incognito search, which may not be representative of all support group resources that patients access. In addition, audiovisual or multimedia resources for support groups and non-English resources were not analyzed. Furthermore, no analysis was performed to address the accuracy of accessed materials.

Conclusion

In conclusion, there is significant variability in the types of support group resources that patients with dermatologic conditions can access from the internet. There are single stand-alone links for support groups in addition to databases of support group links. Most groups are based in the US and run out of nonacademic institutions. Only half of websites provide contact materials or social media resources for patients to access them, which in addition to low understandability and actionability of the resources, can be a significant barrier to utilization by patients. This work can inform improvement of existing online support resources that are created for patients with dermatologic conditions.

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Data availability These data were derived from the following resources available in the public domain: Google, Yahoo, and Bing.

Declarations

Competing interests The authors declare no competing interests.

Conflict of interest The authors declare that they have no conflicts of interest.

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