Facebook Support Groups in Systemic Lupus Erythematosus: A Content Analysis

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Abstract: *Background*: There are many disease-specific groups on Facebook, which offer a convenient way to exchange information and support. This may be particularly helpful for patients affected with uncommon diseases, such as systemic lupus erythematosus (SLE). The content of SLE-related Facebook support groups, however, has yet to be explored and evaluated.

Objective: The objective of this study was to analyze the content of Facebook support groups related to SLE, specifically evaluating the nature of the information shared and the pattern of use.

Methods: Two independent investigators searched for the term "lupus" on Facebook's native search function, from 10/08/2011 to 01/04/2012. Groups related to SLE, operating in English and/or French, and publicly accessible, were included for analysis. Information regarding the purpose of the group, its administrator, as well as the number and type of user-generated contributions were extracted. The content of support groups were then analyzed using a previously developed coding scheme.

Results: We found 173 SLE groups on Facebook containing a total of 42,240 members. Roughly half (53%) of the groups were created for support, while 33% were for disease awareness, and 14% for fundraising. The largest group included 30,972 members and was intended for raising awareness. 3,469 members were found in support groups, representing 8% of the overall membership (but 31% of the overall membership when excluding the largest group). The median number of members was 11 (interquartile range, IQR, 39). The most frequent locations of support groups were the United States (44%), Canada (10%), and United Kingdom (10%). In support groups, the total number of user-generated contributions was 1932, including wall posts (54%), comments (32%), discussion posts (10%), and discussion threads (4%), while the median number of user-generated contributions was 5 (IQR 20).

Conclusions: Support groups for SLE patients represent a substantial proportion of Facebook groups dedicated to SLE. Given their convenience, accessibility, and potential audience, Facebook support groups might represent an efficient way to reach patients with SLE who are internet users and improve their health-related quality of life. Further research is needed to evaluate the effects of this type of support groups on patients with SLE.

Keywords: Systemic lupus erythematosus, lupus, support groups, Facebook.

INTRODUCTION

Increasingly, patients are consulting the internet for information on health-related issues [1]. In addition, a growing number of patients are joining online communities to connect with other people affected with similar conditions, both to share and to receive support and information [2, 3]. This type of interactive online communication between patients provides a virtual social network for people with similar disease experiences [1].

Currently, many disease-specific groups exist on Facebook [4], which, with over 1.1 billion active monthly users, has become the most popular social networking service [5]. It is the second most visited website, surpassed only by Google. However, few investigators have explored disease-specific groups on Facebook with only a handful of studies evaluating their content [1, 4, 6-8]. Until now, no one has assessed Facebook support groups related to systemic lupus erythematosus (SLE).

SLE is an uncommon chronic autoimmune disorder, affecting approximately 0.05% of the population [9]. Patients with SLE might have multiple physical and psychosocial needs and queries [10, 11] that may go unaddressed by health professionals, partly due to lack of time during medical encounters [10, 12]. In addition, due to the relative rarity of the disease, some SLE patients might also feel as though their peers (or even health care providers) do not understand their experiences, leading to a feeling of isolation [10]. As a result, patients with SLE may turn to Facebook groups

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for support and information. Therefore, we aimed to analyze the content of Facebook support groups related to SLE, specifically evaluating the nature of the information shared and the pattern of use.

METHODS

Search Strategy

Using Facebook's native search engine, two study investigators (WSL and EV) searched Facebook groups using the term "lupus", from 10/08/2011 to 01/04/2012. All groups related to SLE, operating in English or French, and publicly accessible, were included for the study. Ethical committee approval was non-applicable to study design.

Data Extraction

An investigator (WSL) extracted information on all eligible groups regarding: 1) general characteristics (i.e., group name, purpose, and URL), and 2) membership and user-generated content (i.e., number of members, discussion posts, wall posts, photos and videos, and date of last post), and for support groups, 3) information on the creator of the group (i.e., approximate age, professional status, and geographical location).

Data Analysis

Two independent investigators (WSL and ZC) classified the purpose of each group based on a content analysis of the group's title, description, information in the "Recent News" section, the discussion posts, and wall posts. The content analysis of the discussion and wall posts was restricted to the first 10 posts displayed on the page of the group. The 10 most recent "wall posts" and the 10 most recent "discussion posts" from all groups were identified and quotes were collected into a database. "Wall posts" are comments made by group members in a Facebook group, enabling them to communicate with all group members. "Discussion posts" represent comments on a thread of a specific topic made by a single member, allowing other group members to respond to the initial comment and any subsequent ones made in relation to that specific topic. It should be noted that, in the most recent version of Facebook, the "discussion posts" function has been removed. Instead, all communication is made *via* "wall posts".

To classify the purpose of the groups, the 2 independent assessors applied a previously developed and agreed upon classification scheme [3], which included the following categories: 1) fundraising groups (aimed to attract financial resources for a cause related to SLE through events, products, or services), 2) awareness groups (developed to bring attention to the importance of SLE in general, or to promote a screening or research program), 3) support groups (created to answer the informational and emotional needs of patients with SLE, their family and/or friends), and 4) promotional groups (created with the purpose of promoting and/or advertising products, services, or external websites that sell products and/or services). Any disagreement between the 2 evaluators (WSL and ZC) were resolved by consensus, and, when necessary, by the involvement of a third party (EV).

The two independent evaluators (WSL and ZC) then classified all posts found in support groups into the following categories: 1) requesting information, 2) providing information, 3) seeking or offering support, 4) advertisement, and 5) irrelevant comments (i.e. having no relationship with group's content).

In addition, posts were flagged as potentially harmful if the evaluators deemed them to contain incorrect, misleading, or potentially harmful clinical information. As above, any disagreement between evaluators (WSL and ZC) was resolved by consensus, and by a third party (EV) when necessary.

Statistical Analysis

Descriptive statistics were used to analyze the characteristics and content of the groups included in the study.

RESULTS

Searching with the term "lupus" in Facebook's native search engine, our initial search identified a total of 218 Facebook groups (Figure **1**). Of these, 29 groups were subsequently removed since they were unrelated to SLE. An additional 15 groups were excluded for having no members, activity, or any description of the group beyond a group title. One group was also excluded as its membership status changed from "open/public" to "closed" (i.e. only accessible to private membership) prior to group analysis.

A total of 173 Facebook groups related to SLE were included for further analysis, containing a total of 42,240 members. Roughly half (53%) of the groups were created for support, while 33% for disease

awareness, and 14% for fundraising. The largest group included 30,972 members and was intended for awareness.

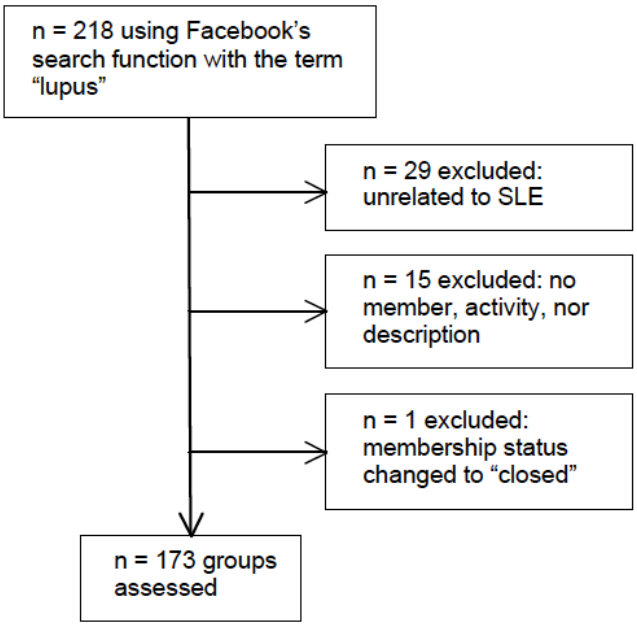

Figure 1: Study Flow Diagram.

In the support groups, a total of 3,469 members were identified, which, when excluding the largest group (i.e. created for awareness and including 30,972 members), represented 31% of the overall membership. The median number of members per group was 11 (interquartile range, IQR, 39). The most frequent support group locations were found to be in the United States (44%), Canada (10%), and the United Kingdom (10%). Another 14% of groups were located either in France, Africa, South America, Australia, New Zealand, or Belgium. The remaining 22% of support groups had insufficient data to allow proper locating.

Among the 92 support groups identified, most (96%) were created by individuals, while 4% originated from national patient organizations. Support group creators were more often females (77%) than males (12%), and the majority (52%) provided no information about their age (Table **1**).

In support groups, the total number of user-generated contributions was 1932, including wall posts (54%), comments (32%), discussion posts (10%), and discussion threads (4%). On average, each group had 20.8 user-generated content, with a standard deviation of 40.9. The median number of user-generated contributions was 5 (IQR 20).

Table 1: Characteristics of Support Groups (n=92)

	Number (%)
Group Creator's sex	
Female	71 (77%)
Male	11 (12%)
No information	10 (11%)
Group Creator's Age	
20-30	13 (14%)
31-40	15 (16%)
41-50	11 (12)%
51-60	4 (4%)
61+	1 (1%)
No information	48 (52%)
Group Location	
Canada	9 (10%)
United Kingdom	9 (10%)
U.S.A	41 (44%)
Other*	13 (14%)
No Information	20 (22%)

*Other: Australia 2, Belgium 1, France 3, Jamaica 1, Morocco 1, New Zealand 1, South Africa 2, Trinidad and Tobago 1, Turkey 1.

Among the total sampled posts (n=447) originating from support groups, 44% were related to seeking or offering support, while 12% and 14% concerned respectively requesting and providing information. A minority of posts was advertisement, and 22% were judged as irrelevant comments. Of all the posts sampled, only 1% was potentially harmful (e.g. inciting to stop appropriate therapies).

Table 2: Type of Information in the Support Groups (n = 447 Sampled Posts)

	No. (%)
Seeking or offering support	196 (44%)
Requesting information	55 (12%)
Providing information	59 (13%)
Advertisements	35 (8%)
Irrelevant comments	97 (22%)
Potentially harmful	5 (1%)

4. DISCUSSION

We found that support groups represent a substantial proportion of Facebook groups dedicated to SLE. We also observed that the most frequent user-generated contribution in SLE support groups relates to seeking or providing support. Very few contributions appeared to be potentially harmful.

With their convenience, accessibility, and potential audience, Facebook support groups may be an efficient way to reach SLE patients and improve health-related quality of life. Social network support groups might offer a number of potential advantages over traditional face-to-face groups [2]. First, timing and scheduling of information delivery is very flexible as information can be shared synchronously through real-time chatting and discussion posts, or asynchronously through wall posts and attached documents. Second, accessibility is facilitated for individuals who would otherwise not have participated in face-to-face groups due to geographical distance, medical condition, or social anxiety. Finally, in social network support groups logistical requirements are low (e.g. no need to book a meeting room). In addition, the typical SLE patient (i.e. a young female) is among the largest demographic of Facebook users. Thus, through social network support groups, patients with SLE could potentially access specific information on their disease, interact with a large network of peers, relate to their experiences, and find support and services, potentially improving their health-related quality of life. Of course there are potential drawbacks to online communities as opposed to face-to-face support groups, such as the need to be literate and have internet access, which might limit accessibility in individuals with low socioeconomic status and/or in developing countries.

Our study is the first to assess Facebook groups related to SLE. Prior investigators have examined other disease groups on Facebook and found a considerable number of patient and caregiver support groups related to malignancies [1, 4, 8]. Bender *et al*. found 620 breast cancer groups on Facebook containing more than 1,000,000 members [6]. The groups were primarily created for patient/caregiver support (47%), but also fundraising (45%), awareness (38%), and product and/or service promotion (9%). The awareness groups as a whole contained by far the most members, but the support-oriented groups were associated with the greatest number of user-generated contributions. Another study identified the 15 largest Facebook groups focused on diabetes management [1]. They observed that more than two-thirds of the posts were dedicated to sharing information and strategies of diabetes management, and almost 29% of posts provided emotional support to other members. Approximately 27% of posts displayed some type of advertising, mostly presented as testimonials promoting non-FDA approved products.

To our knowledge, only one pilot study has evaluated the effect of disease-specific Facebook support groups on affected subjects. Investigators evaluated if a Facebook support group maintained or enhanced the effect of a support summer camp on the health-related quality of life and social functioning of 21 adolescents with inflammatory bowel diseases. The Facebook group was 8 weeks in duration and encouraged campers to continue interacting in a private, protected setting. The health-related quality of life declined from the post-camp to post-Facebook intervention period, while social functioning showed a trend for improvement over the same period, although these findings were not statistically significant [13].

In conclusion, support groups represent a substantial proportion of Facebook groups dedicated to SLE. Given their potential convenience and accessibility, Facebook support groups might represent an efficient way to reach patients with SLE who are internet users and improve their health-related quality of life. Further research is needed to document Facebook support group use for SLE in other languages than English and French, as well as to evaluate the effects of these types of support groups on patients with SLE.

DECLARATION OF CONFLICTING INTERESTS

None.

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REFERENCES

[1] Greene JA, Choudhry NK, Kilabuk E, *et al*. Online social networking by patients with diabetes: a qualitative evaluation of communication with Facebook. J General Internal Med 2011; 26: 287-92. http://dx.doi.org/10.1007/s11606-010-1526-3

[2] Moorhead SA, Hazlett DE, Harrison L, *et al*. A new dimension of health care: Systematic review of the uses, benefits, and limitations of social media for health communication. J Med Internet Res 2013; 15: e85.

[3] Mazzoni D, Cicognani E. Sharing experiences and social support requests in an internet forum for patients with systemic lupus erythematosus. J Health Psychol 2014; 19: 689-96. http://dx.doi.org/10.1177/1359105313477674

[4] Farmer AD, Bruckner Holt CE, Cook MJ, *et al*. Social networking sites: A novel portal for communication. Postgraduate Med J 2009; 85: 455-9. http://dx.doi.org/10.1136/pgmj.2008.074674

[5] Facebook, First Quarter 2013 Financial Summary 2013.

[6] Bender JL, Jimenez-Marroquin MC, Jadad AR. Seeking support on Facebook: A content analysis of breast cancer groups. J Med Internet Res 2011; 13: e16.

[7] Kim C, Kang BS, Choi HJ, *et al*. Nationwide online social networking for cardiovascular care in Korea using Facebook. J of the Am Med Informatics Association: JAMIA 2014; 21: 17-22. http://dx.doi.org/10.1136/amiajnl-2012-001465

[8] Walker KK. A content analysis of cognitive and affective uses of patient support groups for rare and uncommon vascular diseases: Comparisons of May-Thurner, Thoracic Outlet, and Superior Mesenteric Artery Syndrome. Health Communication 2014; 1-13.

[9] Rahman A, Isenberg DA. Systemic lupus erythematosus. New Engl J Med 2008; 358: 929-39. http://dx.doi.org/10.1056/NEJMra071297

[10] Danoff-Burg S, Friedberg F. Unmet needs of patients with systemic lupus erythematosus. Behavioral medicine (Washington, DC) 2009; 35: 5-13. http://dx.doi.org/10.3200/BMED.35.1.5-13

[11] Moses N, Wiggers J, Nicholas C. Persistence of unmet need for care among people with systemic lupus erythematosus: a longitudinal study. Qual Life Res 2008; 17: 867-76. http://dx.doi.org/10.1007/s11136-008-9361-2

[12] Archenholtz B, Burckhardt CS, Segesten K. Quality of life of women with systemic lupus erythematosus or rheumatoid arthritis: domains of importance and dissatisfaction. Qual Life Res 1999; 8: 411-416. http://dx.doi.org/10.1023/A:1008915115370

[13] Plevinsky JM, Greenley RN. Exploring health-related quality of life and social functioning in adolescents with inflammatory bowel diseases after attending camp oasis and participating in a Facebook group. Inflamm Bowel Dis 2014; 20: 1611-7. http://dx.doi.org/10.1097/MIB.0000000000000120

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