The Role of Online Support Communities

Benefits of Expanded Social Networks to Patients With Psoriasis

Shereene Z. Idriss, BA; Joseph C. Kvedar, MD; Alice J. Watson, MBChB, MRCP, MPH

Objective: To determine the demographics, usage patterns, attitudes, and experiences of online support site users.

Design: Online survey.

Patients: A total of 260 subjects recruited from 5 online psoriasis support groups.

Main Outcome Measures: An exploratory analysis was performed to determine demographic and disease characteristics of online support site users. Perceived benefits were also documented.

Results: The mean (SD) age of respondents was 40.1 (11.5) years (range, 18-75 years), most (75.7%) were white, female (60.4%), and college educated (84.3%). Key factors associated with use of online support sites included availability of resources (95.3%), convenience (94.0%), access to good advice (91.0%), and the lack of embarrassment when dealing with personal issues (90.8%). The most common activities were posting messages (65.0%) and searching for information (63.1%). Nearly half of all respondents perceived improvements in their quality of life (49.5%) and psoriasis severity (41.0%) since joining the site. Intensity of participation in online support activities was associated with improved quality of life ($P = .002$), but not with improvements in psoriasis severity.

Conclusions: Our data demonstrate that psoriasis virtual communities offer users both a valuable educational resource and a source of psychological and social support. Such benefits could be further enhanced by physician engagement within these communities.


Psoriasis currently affects approximately 0.6% to 4.8% of the world’s population. In addition to the well-recognized skin and joint manifestations, psoriasis impairs many aspects of individual well-being, including emotional, physical, sexual, and financial status. An estimated 10% of individuals affected by psoriasis have had suicidal ideations, a prevalence surpassing many other medical conditions. As a result, it is a necessity to provide patients with access to psychological support.

Patient support groups are one source of such assistance. They are designed to develop and reinforce positive coping styles known to be associated with improvements in both medical and social outcomes. In the United States, approximately 3% to 4% of the population annually engages in support group activity, and around 25 million Americans are estimated to have participated at some point in their lifetime. There are, however, a number of challenges with traditional face-to-face groups, including geographic barriers, embarrassment, limited space, and time constraints.

The worldwide rise in Internet usage has offered new ways for patients to interact. Despite initial concerns that online activity might lead people to withdraw from social interaction, a number of recent reports have noted that use of the Internet can empower people thus improving social support and self-esteem. There has been a dramatic rise in the number of user-generated health care–related Web sites and online support sites. People with chronic disease are believed to relate best to Web-based information produced by other patients. Internet support groups share common objectives with their face-to-face counterparts but have strengths and weaknesses unique to the online setting. Although online support may lack the immediacy and intensity of a group meeting, it allows members to access information at a time and place of their choice. In addition, it offers individuals the advantage of anonymity and perceived lack of judgment. The benefits of structured, moderated online support programs have
been demonstrated for patients with back pain, heart disease, lung disease, and type 2 diabetes mellitus. However, no structured programs have been developed for patients living with chronic skin disease. Indeed, little is currently known about the online user population living with certain dermatologic conditions, their drive to participate in online support groups, and their experiences within these virtual communities.

We conducted a Web-based cross-sectional survey study of people with psoriasis involved in online support groups. To our knowledge, this is the first survey study to describe user characteristics and the perceived benefits of online support groups in the field of dermatology. This study offers a richer insight into the demographics, usage patterns, attitudes, and experiences of participants involved with these virtual communities.

METHODS

PARTICIPANTS, PROCEDURE, AND DATA COLLECTION

An Internet search to identify virtual psoriasis support networks was performed using the search terms “psoriasis” and “support.” We attempted to capture a representative sample of these virtual communities by identifying 5 forum-type psoriasis support Web sites through which members could directly interact with one another: the National Psoriasis Foundation forum, the Psoriasis Help Organization, the Psoriasis Google Group, the MSN Psoriasis Group, and the Yahoo-based Psoriasis Philippines Online Community Inc. It should be noted that although this cross-section is not a complete sample, these sites were deemed the most established and frequently visited based on the number of members within each group and the online activity that took place on a daily basis. The sites all had an administrator, but the discussions were not formally moderated by a health care provider or coach. We attracted responses on an international scale, with most respondents originating from the United States and the United Kingdom.

Following permission from the administrators of each site, a notice was placed on the site explaining the study objectives and displaying a link to the online survey. No financial incentive was offered to potential participants. Data collection was performed using a Web-based survey tool (http://www.surveymonkey.com). A first notice was posted on all 5 Web sites in October 2006, and a second was reposted in January 2007 on 3 of the 5 Web sites (we encountered technical difficulties with the 2 remaining sites). Although individual responses were anonymous, the site from which the respondent accessed our survey, also known as the jump site, was tracked.

The study population included all individuals who willingly completed our online survey. Inclusion criteria were the diagnosis of psoriasis, age of at least 18 years, proficiency in English, and membership in an online psoriasis support network. The institutional review board of the Massachusetts General Hospital, Boston, granted ethical approval for the study.

SURVEY ADMINISTRATION AND RESPONSE RATE

In total, we gathered 260 responses. Owing to the nature of this method of data collection, it is difficult to ascertain the response rate because we do not know the total cohort of potential subjects with access to the survey. We were, however, able to estimate a response rate from 2 of the 5 Web-based forums. The US-based National Psoriasis Foundation and the UK-based Psoriasis Help Organization display the total number of views of online postings. By assigning site-specific links to the survey, we were able to determine the total number of replies originating from each site. Of the 214 members of the National Psoriasis Foundation who viewed the link, 55 completed the survey, representing a 25.7% response rate. Accordingly, 106 of 768 members of the Psoriasis Help Organization completed our survey, representing a 13.8% response rate.

SURVEY DEVELOPMENT

The 29-item survey was developed in collaboration with dermatologists, qualitative researchers, and Web usage experts. New questions were created to assess several content areas, including overall attitudes and experiences with online communities, length of use, log-on frequency, and the nature of online activities. Participants were also asked to report on perceived changes in their psoriasis, severity of their illness, quality of life (QOL), and their support network since joining online support groups. These novel questions were pretested by patients and providers but not formally validated. The survey also included several validated measures, such as the Dermatology Life Quality Index (DLQI) and 1 question from the 12-item short-form health survey (SF-12). The DLQI consists of 10 items covering symptoms and feelings, daily activities, leisure, work and school, personal relationships, and treatment. Each item is scored on a 4-point scale, with higher scores indicating greater impairment in QOL. Although no psychometric testing was used to assess the reliability and validity of an online-conducted DLQI, internal consistency and reliability have been demonstrated to be nearly identical for multi-item instruments, whether administered via the Internet or by paper questionnaire.

STATISTICAL ANALYSES

This hypothesis-generating, exploratory cross-sectional study was designed to obtain quantitative data about psoriasis support group users; however, a number of free-text entries allowed us to also gather qualitative data. Responses from all 5 sites were combined for analytic purposes. Log-on frequency was combined with site usage pattern to create a 19-point participation score. Higher scores indicated increased frequency and range of activity. Because this was an exploratory analysis, with no single predictor of interest, incomplete survey responses were not excluded, resulting in variations in sample size for different analyses. Continuous variables were assessed for normality to determine appropriate testing strategies. As a result, nonparametric methods were used, such as the Wilcoxon rank sum test for binary vs continuous variables, the Kruskal-Wallis test for continuous vs categorical predictors, and the Spearman correlation coefficients for continuous vs continuous variables. \( P \leq 0.05 \) was considered significant. Statistical analyses were performed using SAS software (version 9.1; SAS Institute Inc, Cary, North Carolina).

STUDY POPULATION

The study sample consisted of 260 adults. The mean (SD) age of the respondents was 40.1 (11.5) years (range, 18-75 years), most (178) were white (75.7%), female (157 [60.4%]), married (116 [44.8%]), and college educated (193 [84.3%]). A total of 188 (73.7%) reported having...
moderate or more severe psoriasis, and 206 (79.9%) rated their current general health status as average or better. The median DLQI score was 9 [interquartile range, 3-17], signifying that over the past week the disease had a moderate effect on the respondent’s life. The Table provides a summary of the demographic features of the study population. The mean age of the participants at 4 of the 5 sites ranged from 37 to 40 years, and most users at the same sites were female n=103 [53.6%]). Users at the fifth site ranged from 37 to 40 years, and most users at the same sites were predominantly college men with a mean age of 50 years (n=12 [70.6%]). The mean age of the participants at 4 of the 5 sites ranged from 37 to 40 years, and most users at the same sites were female n=103 [53.6%]). Users at the fifth site ranged from 37 to 40 years, and most users at the same sites were predominantly college men with a mean age of 50 years (n=12 [70.6%]).

### Table. Demographic Characteristics of Participants

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Participants, No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex (n = 260)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>103 (39.6)</td>
</tr>
<tr>
<td>Female</td>
<td>157 (60.4)</td>
</tr>
<tr>
<td>Race/ethnic background (n = 235)</td>
<td></td>
</tr>
<tr>
<td>White, non-Hispanic</td>
<td>178 (75.7)</td>
</tr>
<tr>
<td>Asian or Pacific Islander</td>
<td>48 (20.4)</td>
</tr>
<tr>
<td>Other</td>
<td>9 (3.8)</td>
</tr>
<tr>
<td>Marital status (n = 233)</td>
<td></td>
</tr>
<tr>
<td>Married or living with partner</td>
<td>139 (54.7)</td>
</tr>
<tr>
<td>Divorced, widowed, or single</td>
<td>94 (40.3)</td>
</tr>
<tr>
<td>Educational level (n = 229)</td>
<td></td>
</tr>
<tr>
<td>1st-12th grade or GED test</td>
<td>36 (15.7)</td>
</tr>
<tr>
<td>≥1 y of college</td>
<td>193 (84.3)</td>
</tr>
<tr>
<td>Employment status (n = 234)</td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>19 (8.1)</td>
</tr>
<tr>
<td>Employed</td>
<td>154 (65.7)</td>
</tr>
<tr>
<td>Student</td>
<td>11 (4.6)</td>
</tr>
<tr>
<td>Homemaker</td>
<td>28 (11.9)</td>
</tr>
<tr>
<td>Retired</td>
<td>22 (9.4)</td>
</tr>
<tr>
<td>Overall health (n = 258)</td>
<td></td>
</tr>
<tr>
<td>Very good</td>
<td>44 (17.1)</td>
</tr>
<tr>
<td>Fairly good</td>
<td>86 (33.3)</td>
</tr>
<tr>
<td>Average</td>
<td>76 (29.5)</td>
</tr>
<tr>
<td>Fairly poor</td>
<td>45 (17.4)</td>
</tr>
<tr>
<td>Poor</td>
<td>7 (2.7)</td>
</tr>
<tr>
<td>Psoriasis severity (n = 255)</td>
<td></td>
</tr>
<tr>
<td>Mild, &lt;3% of body area</td>
<td>67 (26.3)</td>
</tr>
<tr>
<td>Moderate, 3%-10% of body area</td>
<td>80 (31.4)</td>
</tr>
<tr>
<td>Severe, &gt;10% of body area</td>
<td>47 (18.4)</td>
</tr>
<tr>
<td>Very severe, &gt;20% of body area</td>
<td>61 (23.9)</td>
</tr>
<tr>
<td>DLQI scores, range (n = 260)</td>
<td></td>
</tr>
<tr>
<td>0-1: No effect at all on patients’ life</td>
<td>52 (20.0)</td>
</tr>
<tr>
<td>2-5: Small effect on patients’ life</td>
<td>47 (18.1)</td>
</tr>
<tr>
<td>6-10: Moderate effect on patients’ life</td>
<td>50 (19.2)</td>
</tr>
<tr>
<td>11-20: Very large effect on patients’ life</td>
<td>81 (31.1)</td>
</tr>
<tr>
<td>21-30: Extremely large effect on patients’ life</td>
<td>30 (11.5)</td>
</tr>
</tbody>
</table>

Abbreviations: DLQI, Dermatology Life Quality Index; GED, General Educational Development.

When asked to rate the usefulness of various sources of support, the Internet was the most commonly cited (225 respondents [86.5%]), followed by physicians (135 [51.9%]), family (107 [41.1%]), friends (85 [37.0%]), and traditional face-to-face support groups (47 [18.1%]). Women were significantly more likely than men to cite the Internet as a useful source of support (125 women [48.1%] vs 100 men [38.5%]; P < .001).

Key factors associated with use of online support sites included availability of resources (225 respondents [95.3%]), convenience (222 [94.0%]), access to good advice (213 [91.0%]), and lack of embarrassment when dealing with personal issues (217 [90.8%]). Anonymity was also an important feature for three-fourths of participants (173 respondents [73.9%]). Moreover, almost two-thirds believed online support enabled them to gain a sense of control over their psoriasis (156 [65.7%]).

Since joining the site, many respondents agreed that they were now more likely to have someone to provide information (173 respondents [75.6%]), someone to count on to listen (135 [59.2%]), and someone to help deal with personal issues (123 [54.2%]).

Figure. Reported changes since joining online support groups. Social support was assessed by averaging responses about the availability of the following types of support: someone to count on to listen, someone to turn to for suggestions about how to deal with a personal problem, and somewhere to turn to for information.

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ties. More active participants were significantly younger in age (P = .05) and more likely to report improvements in their QOL since joining the site (P = .002) than less-active participants. No association was observed, however, between participation scores and improvements in psoriasis severity, or health status.

The QOL scores were analyzed using the DLQI questionnaire. Lower DLQI scores, reflecting better QOL, were associated with a self-report of less extensive psoriasis (P < .001) and better health status (P = .001). Interestingly, individuals with lower DLQI scores were more likely to report that their psoriasis had improved since joining an online support group (P = .04). The DLQI scores were not associated with level of participation in online forums.

A total of 51 respondents (21%) had previously attended a traditional support group. This subset of subjects was further divided into 2 groups: those who currently still attend face-to-face groups (n = 36 [49.3%]) and those who no longer attend (n = 39 [50.7%]). Distance and schedule conflicts were the primary reasons reported for stopping attendance to a traditional group. Ongoing attendees were considerably more likely than those who have ceased attending to perceive benefits in their psoriasis (P = .03) and QOL (P = .01) since using online support groups. They also presented with statistically lower DLQI scores when compared with the second group (7.5 vs 14.0; P < .001). Regardless of whether people continued or had ceased to attend, individuals who had attended a face-to-face group within their lifetime were more likely to have attended college than those who had never attended (P = .01).

**Comment**

The aim of this cross-sectional online survey was to explore who participates in psoriasis online support groups and what they perceive the benefits to be.

**Demographic Considerations**

Our respondents were primarily middle-aged, white, educated women. This is not representative of the wide spectrum of individuals affected by psoriasis in terms of race, sex, and age.21 The lack of any black respondents might be explained by a number of factors. Of the 5 sites, 3 were not based in the United States but in the United Kingdom and the Philippines, which have black populations of around 2% and less than 1%, respectively. In addition, even in the United States the prevalence of psoriasis among African Americans is half that of the white population.1 The well-documented “digital divide” phenomena is another explanation for the characteristics of our respondents,22-24 which may explain why elderly persons, ethnic minorities, and lower socioeconomic groups are underrepresented in our study sample. Perhaps some of these groups are also less likely to complete online surveys when they encounter them.

The predominance of female respondents in our study, however, is in contrast to the general finding that men are more likely to use the Internet.25 The different online activities undertaken by both sexes may account for this overrepresentation of women in online support groups. Women are more likely to use the Internet for interaction and communication, whereas men are more likely to use it to for information gathering or for entertainment.15,26 Indeed, women tend to have larger networks and multiple sources of support, whereas men are inclined to rely solely on their spouses.27

Our study shows that social networks now extend beyond family and friends to include the Internet. Indeed, our respondents most commonly cited the Internet as a source of support ahead of physicians, family, and friends. This demonstrates the Internet’s potential to play an invaluable role both as an information source and social outlet.

**Participation and Activities**

Those unfamiliar with online support sites might view them as a specialized search engine; however, in reality these sites allow people to interact in a variety of ways. Posting messages was a popular activity with two-thirds of our participants. It has previously been established that online support site messaging typically splits into 2 equally sized categories: task-oriented and socioemotional messaging.11 Posting task-oriented messages, either asking for or providing information, was a common activity among our participants. A total of 75.0% of respondents felt the online support site offered them someone to turn to for information, and 64.6% of respondents replied to messages, indicating that member roles can vary from being “patient experts” to “information seekers.” The fact that socioemotional messages are posted on online sites indicates that subjects involved in online support are prepared to discuss personal issues and expand their social network. One respondent described how he succeeded at accomplishing both:

I have made friends through the online group that I now communicate with outside of the support group, and with whom I feel comfortable discussing personal situations and health. This has allowed me to gain and give more one-on-one support.

The presence of “invisible” members has also been noted in the literature.28 These members prefer to participate by reading online posts. One respondent stated, “I am more of a lurker, but offer advice when I feel the need to.” If, and how, these different online personalities benefit from online networks remains a question for future research.

**Relationship with Disease Severity**

The disease characteristics of the online-user population seem to differ from those of the general population with psoriasis. General psoriasis statistics provided by the National Psoriasis Foundation29 state that most individuals with psoriasis have mild disease, and only one-quarter have moderate to severe psoriasis. In contrast, most of our respondents had moderate psoriasis, with approximately half reporting moderate or severe psoriasis. This percentage is noteworthy in that the users of online support groups are twice as likely to be more severely...
affected by their psoriasis than the general population of individuals with psoriasis.

We observed a high level of engagement by people with very severe psoriasis (>20% of body surface area affected), which counters previous reports that individuals with more extensive disease are more likely to adopt avoidance behaviors\(^{29}\) and are less inclined to search for social support.\(^{27}\) Asking comprehensively about the type of support available to patients is crucial because, unlike face-to-face support groups, the anonymity and lack of embarrassment associated with online support may make it a valuable resource for this vulnerable segment of the general population with psoriasis.

**CLINICAL AND PSYCHOSOCIAL EFFECTS OF PSORIASIS**

Our findings show that since joining the online support groups, most respondents perceived improvements in their psoriasis severity, QOL, and support network (including having someone to provide information, someone to count on to listen, and someone to help deal with personal issues). This finding is consistent with previous studies\(^{17,18}\) that demonstrated that online information and online support improve the health status of those who participate. These studies used a standardized 6-week program involving online moderators. By providing more structured online support for patients with psoriasis it may be possible to induce greater therapeutic effect.

The level of engagement itself may be therapeutic because an increased level of participation was linked to perceived improvements in QOL since joining the site. These benefits may be related to the fact that online support groups offer individuals the opportunity to discuss sensitive issues. Writing out one’s thought and feelings is believed to alleviate depression and loneliness, and this type of empowering experience has been linked to better psychological and physical outcomes.\(^{11,31}\)

**LIMITATIONS**

The cross-sectional design of this study does not address the issue of whether participating in online support groups actually has an objectively measurable effect on psoriatic lesions or QOL. Future research that prospectively tracks individuals over time could address these questions. Irrespective, we feel that self-reported improvements in social support, QOL, and disease severity offer valuable information about the potential benefits of online support.

Employing an Internet-based survey tool made it difficult to estimate a response rate or to assess the demographics of the larger population using online support sites. We also pooled results from all 5 online support groups. There may be site-specific characteristics that determine the degree of benefit and support for participants. Owing to the small sample size from some of the sites, we lacked power to look for intersite differences. Our results are likely to be affected by selection bias because respondents may not accurately reflect the users of sites or the broader population with psoriasis, which in turn, may have an impact on the generalizability of our findings. Nonetheless, we do feel that our responses represent the full spectrum of self-reported health status and psoriasis severity. Indeed, it has been suggested that the sample population responding to Internet questionnaires may be more representative than traditional samples because Internet surveys may allow researchers to reach more geographically diverse populations than can be reached by paper-and-pencil questionnaires.\(^{32}\)

**CONCLUSIONS**

Despite efforts from the medical community to provide a wide array of treatment options for the management of psoriasis, treatment plans frequently fail to address the emotional welfare of patients. As noted in a recent study by the National Psoriasis Foundation, patients report feeling that “the public and even their own physicians fail to appreciate the impact psoriasis has on their well-being.”\(^{60}(p240)\)

Our results reinforce the growing belief that the psychosocial aspect of psoriasis should be integrated into clinical care and long-term treatment of this disease.\(^{5,33-35}\) Although clearance of the physical presence of psoriasis may enhance an individual’s well-being in the short-term, the notion of relapse once therapy is withdrawn is a constant psychological burden.\(^{39,35}\) It is therefore crucial that treatment plans for psoriasis include advice on increasing personal control, reinforcement of active coping methods, and encouraging patients to express themselves emotionally and to seek social support.\(^{5,33-40}\) Better understanding by the medical community is required to successfully engender these positive behavioral and attitudinal changes.

Although online psoriasis support groups are still in their nascent stage, they have captured a loyal and growing audience. The emphasis of this exploratory study was to examine the users and the perceived benefits of online psoriasis support groups. At present, these sites are operating independently of health care service providers. The dermatology community should consider leveraging the infrastructure of online support groups to build on delivering personalized and integrated medical care to individuals affected by psoriasis.

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**Author Contributions:** Dr Watson had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. **Study concept and design:** Idriss, Kvedar, and Watson. **Acquisition of data:** Idriss. **Analysis and interpretation of data:** Idriss and Watson. **Drafting of the manuscript:** Idriss and Watson. **Critical revision of the manuscript for important intellectual content:** Idriss, Kvedar, and Watson. **Statistical analysis:** Watson. **Obtained funding:** Kvedar. **Administrative, technical, and material support:** Idriss. **Study supervision:** Kvedar and Watson.
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REFERENCES