Recruiting Patients With a Rare Blood Disorder and Their Caregivers Through Social Media

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BACKGROUND
Recruiting research participants (patients and caregivers) with experiences relevant to rare diseases remains a challenge. Researchers often rely on patient registries, patient advocacy or support groups, and clinical referrals to recruit study participants. Each of these methods presents unique recruitment challenges, including the following:

- Cost
- Geographic dispersion of patients
- Adequate sample sizes

Patients with rare diseases and those who care for them often seek answers to medical questions and support for medical conditions on the Internet. Social media sites, such as Facebook, have been used as forums to connect patients and caregivers. Such forums provide an opportunity for study coordinators to connect with patients and caregivers communicating about the same disease. Facebook pages could allow study coordinators to recruit a geographically diverse set of participants for many types of health-related studies, especially hard-to-reach populations. This method also allows researchers to potentially recruit patient-caregiver groups quickly and inexpensively. However, social media is still a relatively novel communication medium, and little is known about the use of social media in recruiting populations with rare medical conditions.

METHODS

This study is part of a cross-sectional study conducted to better understand patient experiences and behaviors associated with treatments for hemophilia A and their caregivers. The primary objective was to better understand patient-caregiver experiences and behaviors associated with treatments for hemophilia A. The secondary objective was to understand possible sampling bias.

- Adequate sample sizes
- Respondent characteristics were generally similar between those recruited via Facebook versus non-Facebook (Table 1).
- 63.6% of the sample resided in Canada.
- 53.5% of the sample was white (non-Whites were asked only of US respondents).
- Mean age of all respondents: 35.8 years (standard deviation [SD] = 8.3), similar to those recruited through more standard methods.

RESULTS

- 188 individuals responded to survey invitations, and 101 (53%) completed the questionnaire.
- 44 respondents did not complete the questionnaire for various reasons: ineligible to participate, requested more information, or never received the questionnaire (n = 101), and started but did not complete the screening questionnaire (n = 101).
- The survey was closed after the 101st questionnaire was completed.
- Most respondents were recruited via the Canadian Hemophilia Society (43%)

Figures 1-3. Facebook Invitation Post

Table 1. Respondent Characteristics by Recruitment Mode (N = 101)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Non-Facebook (80)</th>
<th>Facebook (21)</th>
<th>Total Survey (N = 101)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of patient in years</td>
<td>36.4 (9.3)</td>
<td>37.1 (6.4)</td>
<td>37.0 (8.2)</td>
</tr>
<tr>
<td>Employment status, n (%):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full-time</td>
<td>27 (35.3)</td>
<td>11 (52.4)</td>
<td>38 (37.6)</td>
</tr>
<tr>
<td>Part-time</td>
<td>26 (32.5)</td>
<td>5 (23.8)</td>
<td>31 (30.6)</td>
</tr>
<tr>
<td>Student</td>
<td>3 (3.8)</td>
<td>1 (4.8)</td>
<td>4 (3.9)</td>
</tr>
<tr>
<td>Retired</td>
<td>1 (1.2)</td>
<td>1 (4.8)</td>
<td>2 (2.0)</td>
</tr>
<tr>
<td>Other</td>
<td>8 (10.0)</td>
<td>2 (9.5)</td>
<td>10 (9.9)</td>
</tr>
<tr>
<td>Education, n (%):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school diploma or equivalent (e.g., GED)</td>
<td>15 (18.7)</td>
<td>14 (66.7)</td>
<td>29 (28.8)</td>
</tr>
<tr>
<td>Some college or technical school</td>
<td>16 (20.0)</td>
<td>5 (23.8)</td>
<td>21 (20.8)</td>
</tr>
<tr>
<td>Bachelor’s degree or higher</td>
<td>17 (21.3)</td>
<td>1 (4.8)</td>
<td>18 (17.8)</td>
</tr>
<tr>
<td>Graduate or professional</td>
<td>1 (1.2)</td>
<td>1 (4.8)</td>
<td>2 (2.0)</td>
</tr>
<tr>
<td>Gender, n (%):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>52 (65.0)</td>
<td>21 (100.0)</td>
<td>73 (72.3)</td>
</tr>
<tr>
<td>Female</td>
<td>28 (35.0)</td>
<td>0 (0)</td>
<td>28 (27.7)</td>
</tr>
</tbody>
</table>

DISCUSSION

Facebook was an efficient and effective means of recruiting patients with hemophilia A and their caregivers.

- Respondent characteristics between those recruited by Facebook and those recruited by more traditional means were similar, suggesting that Facebook has the potential to provide unbiased samples.
- Facebook and other social media sites may be low-cost recruitment resources.

CONCLUSIONS

- Patients with rare diseases and those who care for them often connect via social media sites in search of information and support.
- Studies on rare diseases are often underfunded, and Facebook and other social media sites may be low-cost recruitment resources.

REFERENCES


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