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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 clinician referrals to recruit study participants. Each one 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.

### The Situation

- 81% of US adults use the Internet as of September 2012<sup>1</sup>
- 80% of Canadians (aged 16 years and older) use the Internet as of 2010<sup>2</sup>
- 80% of US adult Internet users look for health/medical information online as of September 2012<sup>3</sup>
- 64% of Canadian Internet users search for health/medical information online as of 2010<sup>2</sup>
- 67% of US adults are Facebook users<sup>4</sup>
- 48% of Canadians are Facebook users<sup>5</sup>
- Facebook is already being used as a forum to connect patients.<sup>6</sup>
  - Patients share personal experiences
  - Ask questions and receive feedback from each other
- The use of other social media sites has been successful in recruiting patients<sup>7</sup>
- Few costs, if any, are associated with posting a study invitation on an organization's Facebook Web site

## OBJECTIVE

- The purpose of this study was to describe our experiences with Facebook as a mode of recruitment for patients and caregivers of children with hemophilia A.

## METHODS

- This study is part of a cross-sectional study developed to better understand patient and caregiver experiences and behaviors associated with treatments for hemophilia A.
- Patients and caregivers were recruited via three hemophilia organizations:
  - A Central US state hemophilia organization
  - An East Coast US state hemophilia organization
  - The Canadian Hemophilia Society, national office and local chapters
- Patients and caregivers were invited to complete a Web-based questionnaire via:
  - Postings on each organization's Web site and/or e-mail invitations sent to each organization's member list
  - Advertisements about the study on two organizations' Facebook pages (a Central US state hemophilia organization and the Canadian Hemophilia Society) (Figure 1)
- A nominal donation was made to each organization for their assistance in recruitment.
- Target sample size: 100.

Figure 1. Example Facebook Invitation Post



## RESULTS

- 145 individuals responded to survey invitations, and 101 (70%) completed the questionnaire.
  - 44 respondents did not complete the questionnaire for various reasons: ineligible (n = 19), responded to invitation but never opened the questionnaire (n = 10), and started but did not complete the screening questions (n = 4) or questionnaire (n = 11).
  - The survey was closed after the 101st questionnaire was completed.
- Most respondents were recruited via the Canadian Hemophilia Society (Figure 2).

Figure 2. Number of Completed Questionnaires by Organization

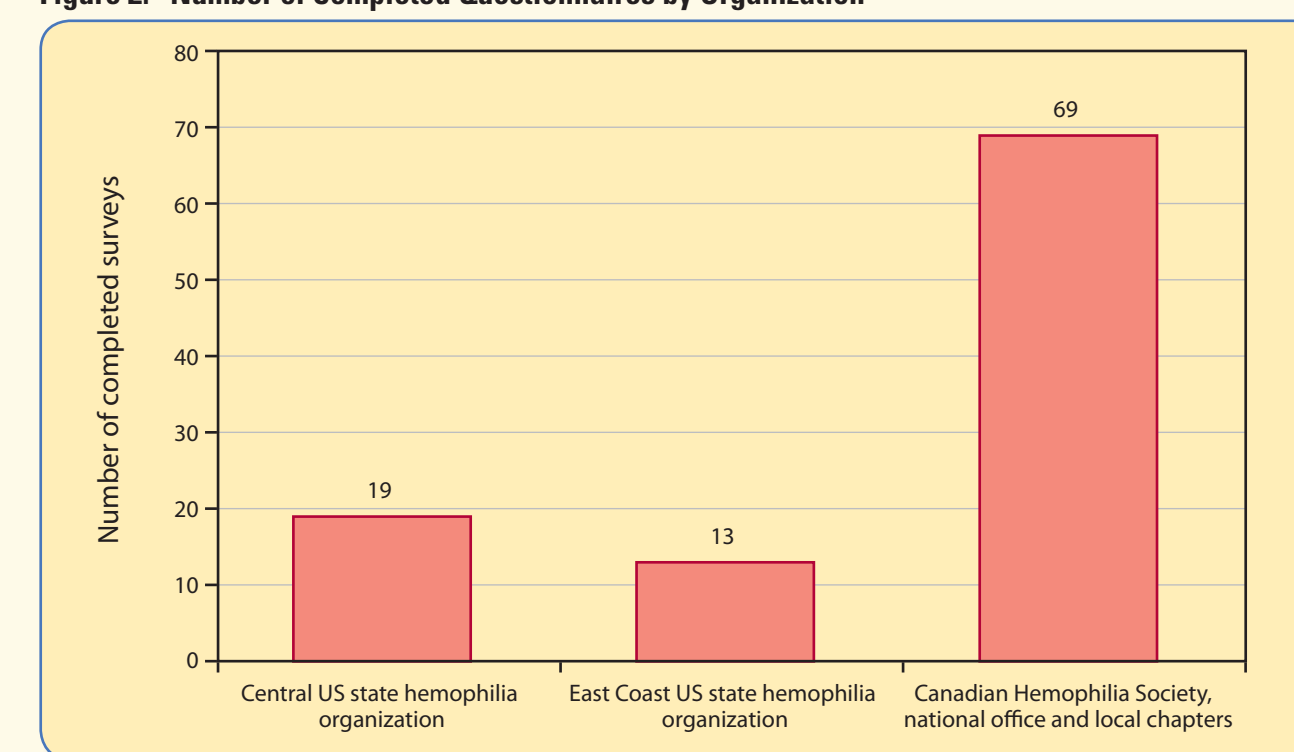
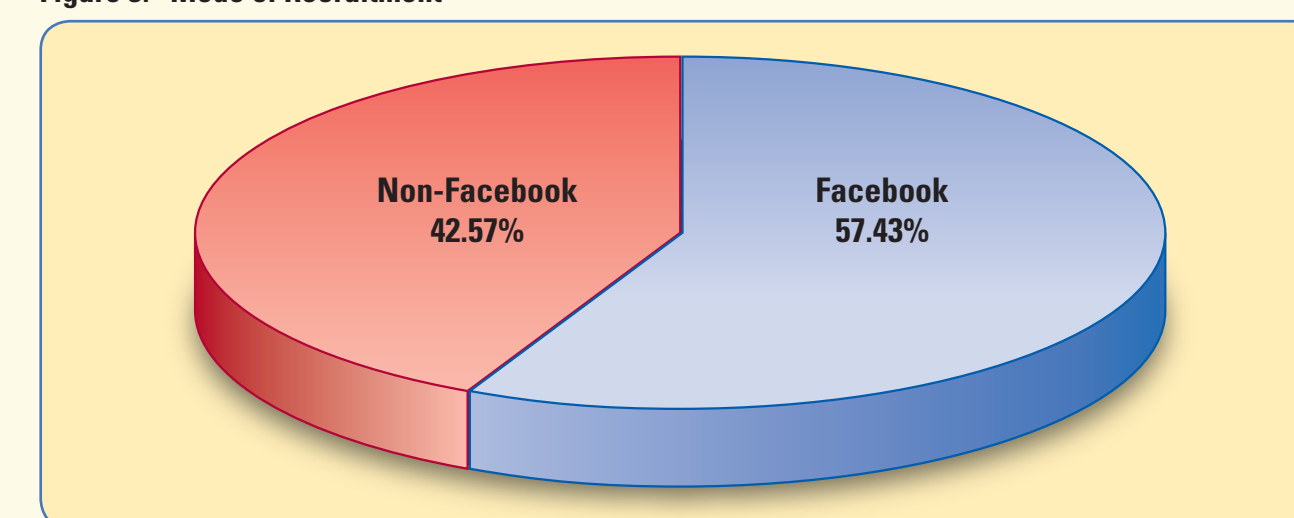


Figure 3. Mode of Recruitment



- Respondent characteristics were generally similar between those recruited via Facebook versus non-Facebook (Table 1).
- 60.4% of the sample resided in Canada.
- 59.5% of the US sample was white (race/ethnicity was 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.

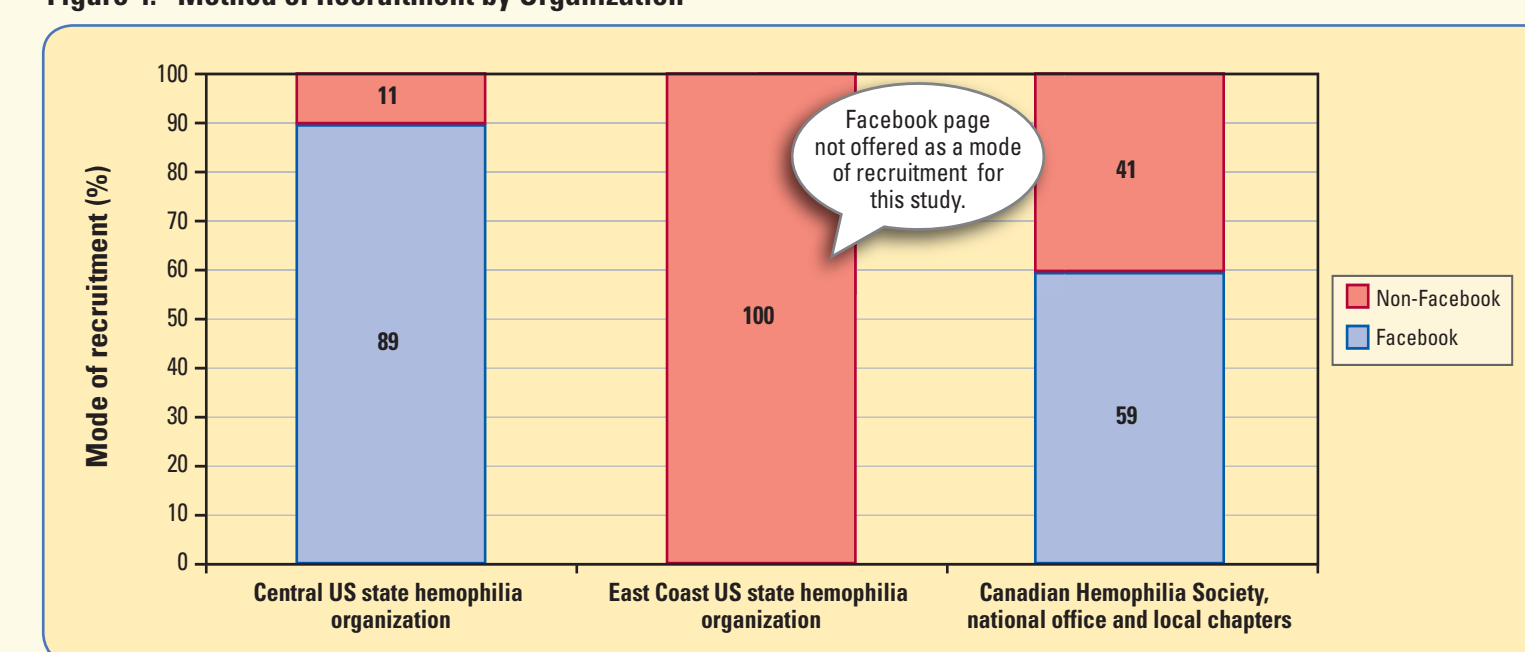
Table 1. Respondent Characteristics by Recruitment Mode (N = 101)

Characteristic	Non-Facebook (n = 43)	Facebook (n = 58)	Total Sample (N = 101)
<b>Respondent type n (%)</b>			
Caregivers	26 (60.5)	42 (72.4)	
Patients	17 (39.5)	16 (27.6)	
<b>Sex (derived), n (%)<sup>a</sup></b>			
Male	22 (51.2)	23 (39.7)	45 (44.6)
Female	21 (48.8)	35 (60.3)	56 (55.4)
<b>Age of patient in years</b>			
n, mean (SD)	17, 35.2 (13.0)	16, 32.5 (11.5)	
Median	31.0	30.0	
Range	18.0-56.0	18.0-58.0	
<b>Age of caregiver in years</b>			
n, mean (SD)	26, 40.0 (9.1)	42, 37.1 (6.4)	
Median	42.0	35.5	
Range	19.0-52.0	29.0-57.0	
<b>Education, n (%)</b>			
Less than high school degree or equivalent (e.g., GED)	0 (0)	2 (3.4)	2 (2.0)
High school or equivalent (e.g., GED)	13 (30.2)	15 (25.9)	28 (27.7)
Technical school or associate's degree (2-year college degree)	4 (9.3)	12 (20.7)	16 (15.8)
College or university	22 (51.2)	25 (43.1)	47 (46.5)
Graduate or professional	4 (9.3)	4 (6.9)	8 (7.9)
<b>Employment status, n (%)</b>			
Employed	24 (55.8)	28 (48.3)	52 (51.5)
Self-employed	4 (9.3)	5 (8.6)	9 (8.9)
Homemaker	6 (14.0)	12 (20.7)	18 (17.8)
Student	3 (7.0)	8 (13.8)	11 (10.9)
Retired	1 (2.3)	1 (1.7)	2 (2.0)
Disabled/unable to work	2 (4.7)	2 (3.4)	4 (4.0)
Unemployed	3 (7.0)	2 (3.4)	5 (5.0)

GED = general equivalency diploma.  
<sup>a</sup> Administered to only caregivers. Patient responses (all assumed to be male) were derived.

- The organization that did not post a study advertisement on Facebook recruited the fewest participants (only 13% of the total respondents) (Figure 4).

Figure 4. Method of Recruitment by Organization



## 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.
- Hemophilia organizations that posted study invitations on Facebook recruited a greater number of study participants using this methodology than more traditional recruiting strategies.

## 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.
- This real-world study emphasizes the value of social media in study recruitment and indicates that it can be an efficient means of reaching large numbers of potential respondents.
- Further research should compare Facebook and non-Facebook patient populations to understand possible sampling bias.

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