

# Social Media Use and Preferences in Patients With Inflammatory Bowel Disease

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**Introduction:** There has been growing interest in social media use in managing chronic illnesses. The aim of this study was to assess social media usage in a large sample of patients with inflammatory bowel disease (IBD).

**Methods:** We performed a cross-sectional study within the Crohn's and Colitis Foundation's IBD Partners' internet-based cohort. We used bivariate analyses to compare patient characteristics by various factors associated with social media utilization. We used logistic regression models to determine factors independently associated with using social media to obtain IBD-related information.

**Results:** A total of 1960 IBD patients were included. Most respondents reported spending between 30 and 60 minutes on social media sites per day. Thirty-two percent of respondents agreed that social media could be useful for disease management. Most respondents agreed that social media should be used to connect patients with IBD-related organizations and to obtain IBD-related information online. Fifty percent of respondents could not rate the quality of IBD information posted online. Concerns surrounding social media use included privacy/confidentiality and lack of trust of information posted. The most frequently used social media website was Facebook. Thirty-two percent of respondents used social media at least once in the last week to obtain or post IBD-related content. Factors independently associated with social media use for IBD included female gender (odds ratio [OR] 1.43; 95% CI, 1.10–1.87), age (OR 0.99; 95% CI, 0.98–1.00), remission (OR 0.63; 95% CI, 0.50–0.79), and a diagnosis of Crohn's disease (CD) rather than ulcerative colitis (UC) (OR 0.74; 95% CI, 0.58–0.93).

**Conclusions:** Patients with IBD in this cohort expressed a substantial interest in using social media to aid in disease management. Use was higher in younger patients, females, and patients with active disease. Most patients were unsure of the quality of information posted online, which represents opportunities for clinicians to guide patients to appropriate resources.

**Key Words:** inflammatory bowel disease, social media, digital health, internet

## INTRODUCTION

There has been a growing trend in utilizing social media in the management of chronic illnesses over the past several years. Social media is defined as any website or mobile application that allows users to share and create content across various digital mediums.<sup>1</sup> Social media use has been examined as a tool for disease management in chronic illnesses such as asthma, diabetes, cardiac disease, and tobacco abuse, but it

is less known with respect to its use in patients with inflammatory bowel disease (IBD).<sup>2–5</sup> Patients with chronic illnesses often utilize social media to discuss their disease with peers, obtain educational disease-related information, communicate with their physicians, and communicate with patient-related organizations. In 2016, Frohlich et al examined online communities to understand how IBD patients with social media construct their own meanings of living with a chronic illness.<sup>6</sup> The authors found that patients with IBD often turn toward online communities and utilize social media to obtain peer support. Information technology continues to change the way patients interact with their physicians. As of 2008, 93% of adolescents (ages 12–17) used the internet, and 80% had internet access in their homes. These numbers have likely increased over the past few years.<sup>7</sup> A 2011 study assessed the use of social media, text messaging, and email preferences of patients with asthma 12–40 years old. The authors found that 58.9% of participants had interest in receiving asthma information through email, 23.2% through Facebook, 34.1% through Myspace, 34.1% through text messaging, and 3.7% through Twitter. Text messaging and Facebook were used by 65% of respondents to receive asthma-related information.<sup>2</sup> As the use of social media evolves, it is unclear which venues of social media patients with

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IBD will prefer. Understanding patterns of use, patient preferences, their desire for clinicians, options for hospitals and other organizations to provide educational information via social media, and barriers to social media usage will allow clinicians to interact more effectively with their patients and potentially improve the management of their condition.

In 2016, a cross-sectional survey of 118 patients at the Boston Medical Center and the University of South Alabama assessed IBD patient's patterns of social media use, barriers to use, and patient preferences for having clinicians, hospitals, and IBD patient-related organizations contributing disease-specific information via social media.<sup>8</sup> We found that most IBD patients spent at least 1 hour per day on social media. The most frequently used IBD-related Web site was [www.crohnscolitisfoundation.org](http://www.crohnscolitisfoundation.org). We found that roughly one third of patients believed that social media could be useful in the management of their IBD with high-frequency social media users, as defined by more than 2 hours of use per day. Most patients (54%) were interested in obtaining IBD-related information from their gastroenterologist through social media. Privacy and confidentiality concerns were the primary barriers to social media use. Lastly, most patients were unsure of the quality of IBD information posted online. A major limitation of this study was its small sample size and limited geographical diversity. Prior studies have examined the quality of IBD information posted online, with the overall quality being poor.<sup>9</sup> The aim of this study was to assess social media use, patient preferences, and barriers to use in a large internet cohort of patients with IBD to target future appropriate educational interventions.

## METHODS

We used an internet-based cohort, IBD Partners, to investigate social media use and preferences in patients with IBD in a cross-sectional study. IBD partners is an online cohort study with over 15,000 patients enrolled. More information regarding the specifics of the partner's cohort is described elsewhere.<sup>10</sup> Patients fill out surveys biannually on disease status, activity, medication use, and patient-reported outcomes. Various modules can be included with follow up surveys. In IBD Partners, disease activity is measured through the short Crohn's disease activity index (sCDAI) for CD and the simple clinical colitis activity index (SCCAI) for UC patients; a sCDAI <150 or a SCCAI ≤2 are considered to be in remission.<sup>11, 12</sup>

### Social Media Survey

We developed a 31-question survey (see online supplemental material) to assess patterns and barriers to social media use among IBD patients. The survey assessed patient preferences for the use of social media in the management of their IBD and their beliefs about the quality of IBD information posted social media. The survey expanded upon our prior

survey of IBD patients at 2 institutions.<sup>8</sup> Surveys were completed between July 12, 2016, and April 11, 2017, until a goal of at least 1900 patients completed the survey.

## Data Collection and Management

IBD Partners is a novel e-cohort with over 15,000 adult patients with self-reported IBD enrolled. In a separate validation study of a subset of participants, over 95% had their IBD diagnosis confirmed by their provider.<sup>13</sup> Biannual surveys are released for follow-up. Modules can be added to assess independent research questions to each follow-up interval. The cohort also serves as a vehicle for recruitment to other studies and registries.<sup>14, 15</sup>

## Statistical Analysis

We performed bivariate analyses to evaluate associations between social media use for IBD and various demographic and disease-related variables. Continuous variables were presented as means and SD, although the categorical variables were reported as percentages. Comparisons were made using the Pearson  $\chi^2$  test for categorical variables and the Student *t* test or Mann-Whitney *U* test for continuous variables. Logistic regression models were then utilized to investigate independent associations between social media use for IBD and disease and demographic factors (such as medications). All statistical analyses were performed using STATA version 14.0 (College Station, TX, USA). *P* values <0.05 were considered statistically significant. The University of North Carolina–Chapel Hill institutional review board approved the study protocol.

## RESULTS

A total of 2830 individuals were offered the survey module, and 1960 participants completed the social media survey for a response rate of 69.3%. The median age of the survey group was 42.5 years, 74.8% were female, and 64.9% had Crohn's disease. **Table 1** summarizes the characteristics of the study population that completed the survey. There were no differences between responders and nonresponders with respect to remission status, race, and disease type. However, responders were more likely to have CD, be younger in age, and be female.

When amount of time spent on social media was assessed, the majority (56.7%) reported spending between 30 minutes and 1 hour on social media per day. Twenty-three percent of respondents spent 1 to 2 hours on social media per day, whereas 9% spent 2 to 3 hours per day. Social media use was higher in patients with active disease as compared with patients whose disease was in remission (OR 0.63; 95% CI, 0.50–0.79).

When we assessed utilization of social media for obtaining IBD-related information, we found that most respondents (68.3%) did not use social media to obtain or post IBD-related information in the previous week, although 10.3% reported posting or obtaining IBD-related information on at least 1 day

**TABLE 1.** Characteristics of the Population of Patients With IBD in the Crohn's and Colitis Foundation Partners Cohort Who Reported Information on Social Media Usage and Preferences

Characteristic	Population (n = 1960)	
	N	% or mean (SD), median (IQR)
IBD type		
Crohn's disease	1271	64.9
UC/IC	689	35.1
Gender (% female)	1466	74.8
Race (% Caucasian)	1732	94.8%
Age	1958	42.5 (14.4)
Age at IBD diagnosis	1958	28.7 (12.9)
US Resident	1828	93.3
Remission (by disease activity indices, % yes)	1077	62.9
Education		
≤ high school	100	5.3
Some college	303	16.2
College graduate	827	44.1
Graduate school	646	34.4
History of hospitalization	1348	68.8
History of surgery	843	43.4

in the prior week. Eight percent of respondents used social media to obtain or post IBD-related information every day in the past week. When examining social media use to obtain or post IBD-related information within the last 24 hours, 83.3% of respondents reported no use, and 16.7% reported social media use to obtain or post IBD-related information at least once.

**TABLE 2.** Factors Associated with Social Media in Patients with IBD<sup>a</sup>

Characteristic	OR (95% CI)
Sex (Female)	1.44 (1.10–1.87)
Age	0.99 (0.98–1.00)
Remission <sup>b</sup>	0.67 (0.53–.849)
Education	0.83 (0.64–1.08)
IBD type (reference = CD)	0.82 (0.64–1.04)
Immunomodulator use	1.07 (0.84–1.36)
Biologic use	1.56 (1.24–1.96)
Steroid use	1.57 (1.09–2.27)

<sup>a</sup>Adjusted for demographic factors, remission status (as measured by simple clinical colitis activity index or short Crohn's disease activity index), education, IBD type, and IBD medications

<sup>b</sup>Remission coded such that those in remission are less likely to use social media as compared with those with active disease

Logistic regression models were used to examine independent factors associated with social media use for IBD and can be seen in [Table 2](#). Variables independently associated with social media use included female gender (OR 1.4; 95% CI, 1.10–1.87), remission status (OR 0.67; 95% CI, 0.53–0.84), biologic use (OR 1.56; 95% CI, 1.24–1.96), and steroid use (1.58 95% CI, 1.09–2.27)

When respondents were asked for what purpose social media should be used, 57.9% agreed it should be used to connect patients with IBD-related organizations, 53.7% agreed it should be used to connect patients with other patients, 30.1% agreed it should help patients connect with their gastroenterologist, and 57.6% agreed it should be used to obtain IBD-related information. Overall, 32.9% felt that social media can be useful for disease management, whereas 21.9% did not, and 45.8% were neutral. Forty-three percent believed that using social media to get IBD information is easy, 26.5% felt it was enjoyable, 48.3% agreed it was convenient, and 29.8% agreed it could improve their disease.

When we examined the amount of social media accounts respondents followed or participated in, we found that 21.3% followed 1–50 social media accounts, 23.9% followed between 101–300 accounts, and 17.8% followed more than 500 accounts. When examining IBD-specific social media accounts followed, most (51.9%) subscribed to 1–5 IBD online groups, whereas 45% did not belong to any IBD online groups. Most (90.5%) do not follow an IBD-related Twitter account; 6.7% follow 1–5 IBD-related Twitter accounts, and 1.4% follow 6–11 IBD Twitter accounts. Most (56.6%) do not follow an IBD-related Facebook account, and 39.4% of respondents follow 1–5 IBD-related Facebook accounts. The most frequently used social media websites were Facebook (79.8%), Instagram (29.1%), and LinkedIn (26.8). The most frequently used IBD-specific social media website was the Crohn's and Colitis Foundation Facebook page (79.8%). Other frequented social media Web sites included patientslikeme.com (23.4%), MyCrohnsteam.com (8.8%), and the Crohn's and Colitis Foundation Twitter account 8.2%. With respect to IBD-related blogs, most respondents (77.4%) did not follow any IBD-related blogs, and 21.5% follow 1–5 blogs. Most (88.2%) did not spend any time commenting on IBD-related blogs, whereas 10% spent 1–15 minutes per day posting on IBD-related blogs.

When patient preferences for their gastroenterologist's involvement in social media were assessed, 37.4% expressed interest in obtaining IBD-related educational information from their gastroenterologist, but 31% were not interested. Twenty-five percent felt their gastroenterologist should post IBD-related patient-educational information on social media, 20.3% disagreed with this sentiment, and 53.9% were neutral.

When we assessed barriers to social media use, the leading concerns were privacy/confidentiality (68.3%) and lack of trust of information posted (42.6%). When asked to assess the quality of IBD-related information posted online (see [Fig. 1](#)), 50% of respondents could not rate the quality of IBD information

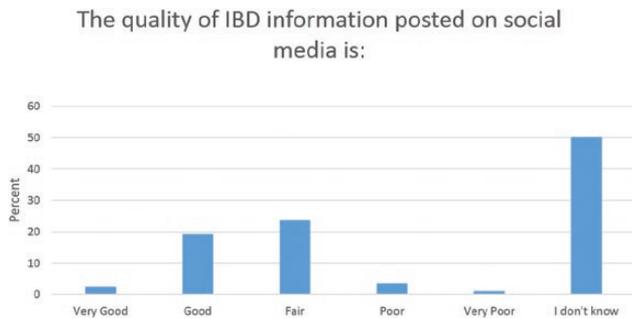


FIGURE 1. Respondents views on the quality of inflammatory bowel disease information posted on social media.

posted online, and 61.2% felt the quality of this information could be improved if the Crohn's and Colitis Foundation contributed to posts, whereas 46% felt the quality could be improved if their gastroenterologist contributed to social media posts.

## DISCUSSION

Over the last decade, social media use among US adults has nearly tripled: roughly 20% of the US population reported social media use in 2008, compared with nearly 70% of the US population in 2016.<sup>16</sup> Social media in healthcare has had an ever growing presence over the past several years, and usage among patients and providers is increasing. Patients are turning toward social media to obtain disease-related information, connect with peers, and connect with patient-focused organizations and their physicians. Practitioners are also partaking in social media to network with individuals within their field, share their research developments, and provide quality disease-related information for patients. Prior work by our group examined a small cohort of 118 patients and found that high-frequency social media users (defined as social media use for greater than 2 hours per day), as compared with low-frequency social media users, felt that social media could be useful for managing their IBD.<sup>8</sup> The majority of patients surveyed expressed interest in obtaining IBD-related information through social media from patient-related organizations and their providers. Given the small sample size of this cohort, we sought to improve generalizability by surveying patients within the Crohn's and Colitis Foundation partners internet-based cohort.

In this larger cohort, we demonstrated that the majority of patients with IBD are spending between 30 minutes and 1 hour on social media per day. We question whether this may be an underestimate as respondents may under-report the amount of time spent on social media in a given week. The majority of respondents reported involvement in IBD-related online groups. Social media use was higher in patients with active disease. Perhaps those with more active disease are more inclined to search for disease-related information online or create posts and generate content about their experience living with a chronic illness. More work is certainly needed in this

area so that we can better understand why patients with more active disease are more likely to utilize social media. While it is understandable that sicker patients may be more apt to turn to social media for support, there is certainly some concern that sicker patients may be more vulnerable to poor-quality information, which is abundant throughout social media. One third of survey respondents expressed interest in having their gastroenterologist generate social media content, and most respondents felt that overall quality of content would improve if their physician and patient-related organizations contributed to disease-related information posted on social media. With the rising use of social media, clinicians should consider increasing their presence on social media to engage in discussion and disseminate factual content.

Two observations were made when more specifically analyzing patient interest in utilization of social media for IBD-related information: The majority of respondents are not actively using social media to obtain IBD-related information. However, a small group (nearly 10% of patients) reported social media use for obtaining IBD-related information on a daily basis within the previous week. Variables independently associated with use were female gender, active disease, and a diagnosis of Crohn's disease rather than UC. A study recently published by Szeto et al examined how an adolescent population utilized social media to obtain disease information, communicate with providers, and connect with other patients. They found that while few adolescents used social media for obtaining disease-related information or managing their disease, the majority of participants expressed interest in using social media in the future.<sup>17</sup> Our findings may suggest that the majority of IBD-related content posted on social media by patients is driven by a minority of patients. We recently collaborated with researchers at the Boston University School of Emerging Media to explore the general public's media usage surrounding IBD. We surveyed a nationally representative sample of 1200 respondents and found that—interestingly—participants who most frequently engaged in producing social media content were less knowledgeable about IBD, thus, highlighting the potential for a dangerous cycle of misinformation to be spread.<sup>18</sup> Our findings suggest that there may be a systemic lack of quality IBD information posted on social media. Therefore, greater efforts may be needed by physicians and patient-related organizations to contribute quality content on social media. For instance, the Crohn's and Colitis Foundation hosts frequent chats on both Twitter and Facebook. These are typically moderated by patient advocates and expert IBD physicians, which may represent one valuable route of distributing trusted patient-education information.

While the majority of respondents did not report using social media to obtain IBD-related information, most respondents did agree that social media serves a role in connecting patients with other patients and IBD-related organizations. Given the interest in social media for these aspects of IBD, we

anticipate an increase in the number of patients with IBD using social media to obtain disease-related information.

While patients, physicians, and healthcare organizations use social media on a routine basis to share content, researchers are beginning to utilize social media to survey patients without the inherent response bias that is seen traditional office-based surveys.

The main strength of this study includes the large number of respondents surveyed and increased geographical diversity compared with our prior study assessing social media usage in patients with IBD.

A limitation of this study is the cross-sectional design. Additionally, we recruited from an internet-based cohort, which is likely not representative of the IBD population in general because this is a group of IBD patients already widely using the internet. Lastly, our study provides a general sense of increasing online traffic with respect to IBD; however, we did not specifically assess the type of IBD information patients are seeking. Nevertheless, identifying trends in this internet-savvy cohort will still help us to understand social media usage and preferences among IBD patients. Participants who completed surveys on social media usage were more likely to be younger in age and female. However, this is somewhat representative of the US population at large. According to Pew Research statistics, 72% of US females reported using social media in 2016, compared with 66% of men.<sup>16</sup> While respondents in our survey were likely to be younger in age, clinicians should not assume that older patients are not using social media. In fact, Pew research reports that while 34% of adults over the age of 65 report social media use on a daily basis, 64% of adults ages 50–64 report daily usage, 80% of adults ages 30–49 report daily usage, and 86% of adults ages 19–29 report daily usage. While the largest percentage of social media usage is occurring among younger individuals, the age gap seems to be closing and will likely to continue to do so over the next few years.<sup>16</sup>

This internet-based cohort of patients expressed an interest in using social media to obtain disease-related information. This study highlights a need for physicians and patient-related organizations to have an active role in social media to improve the quality of content posted. As most patients were unsure of the quality of information posted online, this area merits further

research. Future studies should assess the quality of IBD information on social media and the effectiveness of communication via social media as a means to improve patient education and outcomes.

## SUPPLEMENTARY DATA

Supplementary data are available at *Inflammatory Bowel Diseases* online.

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