

Social Media Use in Patients with Inflammatory Bowel Disease

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(Inflamm Bowel Dis 2016;00:1–8)

With the recent growth in the use of the Internet, patients with chronic illnesses are using the web as a resource in the management of medical conditions. Internet use has become more important than ever; we use it to find jobs, watch movies, and access health care information. Census data from 2013 shows that 84% of households had computers, 74% of households had internet access, and 73% of households had a high-speed connection. Computer ownership is more common in young families, Asians, whites, individuals with higher education status and in metropolitan areas. Blacks and nonhispanics had the lowest computer ownership and internet usage.[¶] As internet use increases in the United States increases, so does the prevalence of social media use.

This review will discuss the use and quality of social media in patients with Inflammatory Bowel Disease (IBD) and other chronic medical conditions. We will also highlight areas of further research that are needed in the field.

SOCIAL MEDIA PREVALENCE

Social media is defined as any online venue that allows users to network and share information. This definition is broad and encompasses social networking sites (Facebook, Twitter, and Instagram), content communities (YouTube), and collaborative projects (Wikipedia).[¶] As of 2011, Facebook had upward of 750 million users worldwide and 157 million users in the US, a number that has been growing substantially.[¶]

As of 2010, Twitter had 280 million users.[¶]

A survey conducted in 2014 by the Pew Research Center found that Facebook remains the most popular social media site. Although other sites such as Twitter and LinkedIn have seen a significant increase in users, most (71%) of the Internet users are on Facebook. Social media usage is widely prevalent among

adults 18 and older. Fifty-eight percent of this age group use Facebook, 23% use LinkedIn, 22% use Pinterest, 21% use Instagram, and 19% use Twitter.[¶]

THE TRANSITION FROM THE INTERNET TO SOCIAL MEDIA

Recently, the term “e-patient” has been coined to describe patients who look online for health information. Most (61%) of the adults look online for health information, and 39% of adults use social networking sites such as Facebook or Myspace, whereas 12% of adults use Twitter to obtain health information. A recent survey found that 60% of adults said that the information found online affected a decision about how to treat an illness or condition. A transition from internet usage to social media use to obtain health-related information is currently underway. Roughly, one-third of adults access health-related social media content.[¶]

Use of the Internet and social networking is not just limited to young adults. Usage among older adults (defined as age 65 and older) is growing. Approximately, 1 in 3 older internet users access social networking sites such as Facebook and LinkedIn, and approximately 1 in 5 older internet users contribute to these sites regularly by tagging, categorizing, or commenting on online medical content.[¶] Given that older adults are the fastest growing group of novice computer users, providers must be aware that their older patients may also be seeking health information online.[¶] Future research should examine how older adults with IBD obtain information online. Physicians, providers, and other medical organizations should be aware of the venues patients use to seek health-related information.

As the general public begins to embrace social media, the scientific community has as well. A survey of 3748 scientists in the American Association for the Advancement of Science found that 22% of scientists felt it was very important or important for them to promote their scientific findings through outlets such as Facebook and Twitter, whereas 77% said it was not too, or not at all important for career advancement to promote their scientific findings through social media. It is evident that a large minority of scientists feel that their work can be promoted through social media use, however, most scientists surveyed did not agree with this. In fact, 79% of scientists felt that social media did not distinguish between well-founded and not well-founded scientific findings. Roughly half (52%) of scientists felt that simplification

Received for publication October 18, 2015; Accepted XX, XXXX.

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The authors have no conflict of interest to disclose.

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DOI 10.1097/MIB.0000000000000713

Published online.

of research findings through social media is a major problem.¹⁰ Social media use in the scientific community is expected to increase because social media sites become more trusted, although clearly limitations exist.

SOCIAL MEDIA AND MOBILE HEALTH APPLICATIONS

There is increasing use of smartphone technology to obtain health-related information. Approximately two-thirds of Americans own a smartphone. Nineteen percent of Americans rely on smartphones for accessing online services and information. Interestingly, smartphones are not just limited to those of higher socioeconomic status. Thirteen percent of Americans with an annual income of less than 30,000 per year are smartphone-dependent. A majority (62%) of Americans have used their smartphone to obtain health-related information.¹¹ There are roughly over 40,000 health-related apps that can be accessed with smartphone technology and this number has been growing rapidly.¹² Numerous smartphone applications exist for IBD. We performed a search of the Apple iTunes store (August 28th, 2015) for the keyword “IBD.” Our search revealed applications, including, but not limited to, Crohn’s Diary (allows users to track triggers of disease symptoms), Wellness Widget (allows users to track number of bowel movements, abdominal pain, fatigue, and overall well-being), GI monitor (allows users to log symptoms to provide data to their doctors), and myIBD (in addition to logging symptoms, contains educational information about IBD) (Table 1).

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With the increasing usage of smartphone technology for disease management, physicians must be aware that this is a venue patients may use. Boudreaux et al published an article that offers physicians’ advice for selecting mobile health applications for their patients. Currently, the Food and Drug Administration (FDA) does not regulate smartphone health applications but organizations have been created with the goal of certifying smartphone health applications. Health on the Net Foundation Code of Conduct (<http://www.healthonnet.org>) and the Information Standard (<http://www.theinformationstandard.org>) review smartphone health-related applications to ensure that they meet predetermined standards, such as ensuring information contained in an application is evidence based.¹³ It is important for physicians or medical professional societies to pilot test applications before recommending them to patients. Physicians must be comfortable with the applications’ interface to understand how patients may be using smartphone applications to keep track their health. Currently, 25% of physicians use social media daily as part of their clinical practice.¹⁴ As more physicians begin to incorporate social media and smartphone technology into their practice, it will be crucial that the quality of information provided by these venues is at a high standard (Table 2).

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PATIENT PREFERENCES FOR SOCIAL MEDIA IN DISEASE MANAGEMENT

As discussed previously, health care social media usage has increased substantially over the last decade. Patients are using social media to make health care decisions and network with other

TABLE 1. IBD Mobile Phone Applications

Application	Average Rating	Description	Cost
Wellness widget (available for iOS 3.1.3 or greater), English	4+/5	Track symptoms and pain levels Create a report of how you feel Set up reminders to take a medication, refill prescription, or see your doctor	Free
GI Monitor (available for iOS 6.0 or greater), English, French, German, Italian, Spanish	4+/5	Track symptoms and pain levels Monitor stress patterns Communicate with other patients through app Log meals	Free
MyIBD (available for iOS 6.0 or greater), English and French	4+/5	Track symptoms Chart entries over time Learn information about IBD	Free
Crohn’s diary (available for iOS 6.0 or greater), English, German	4+/5	Track symptoms and pain Record triggers such as food, stress, location, activity, weather patterns Record medications and side effects Management analysis function tracks helpful Rx Track appointments, test results, vitals, procedures, surgeries, etc	\$4.99

TABLE 2. Potential Future Areas of Research

Examine how older adults (aged > 65) obtain IBD information online
Quality assessment of IBD online information on sites, including Twitter, Facebook, Instagram, etc
Examine discrepancy between interest in obtaining information online and actual web-based usage
Assessment of social media preferences and usage in patients with IBD
Assessing efficacy of mobile phone applications in better symptom control
Assessing potential of mobile phone applications and social media to predict IBD exacerbations
Explore how patient portals such as EPIC, MyChart effect patient satisfaction and management of IBD

patients to share information about their illnesses. Patients are also looking for their providers on social media. In fact, more than half of patients search for their provider online before seeing them in the office. A survey of approximately 1000 patients revealed that more than 70% of patients would want to use social media as a tool to manage their health.¹⁵ Another survey revealed that 85% of patients believe that digital communication is as helpful if not more helpful than communicating in-person or through phone with their health care provider.¹⁶

A survey of 485 health care providers revealed that 79% of residents and 42% of attending physicians used online social media. Of this cohort, one-third reported patient–doctor interaction online.¹⁷ As patient use of social media to obtain health-related information increases, individual providers, group practices, and hospitals should take an active role in using social media to provide health-related information.

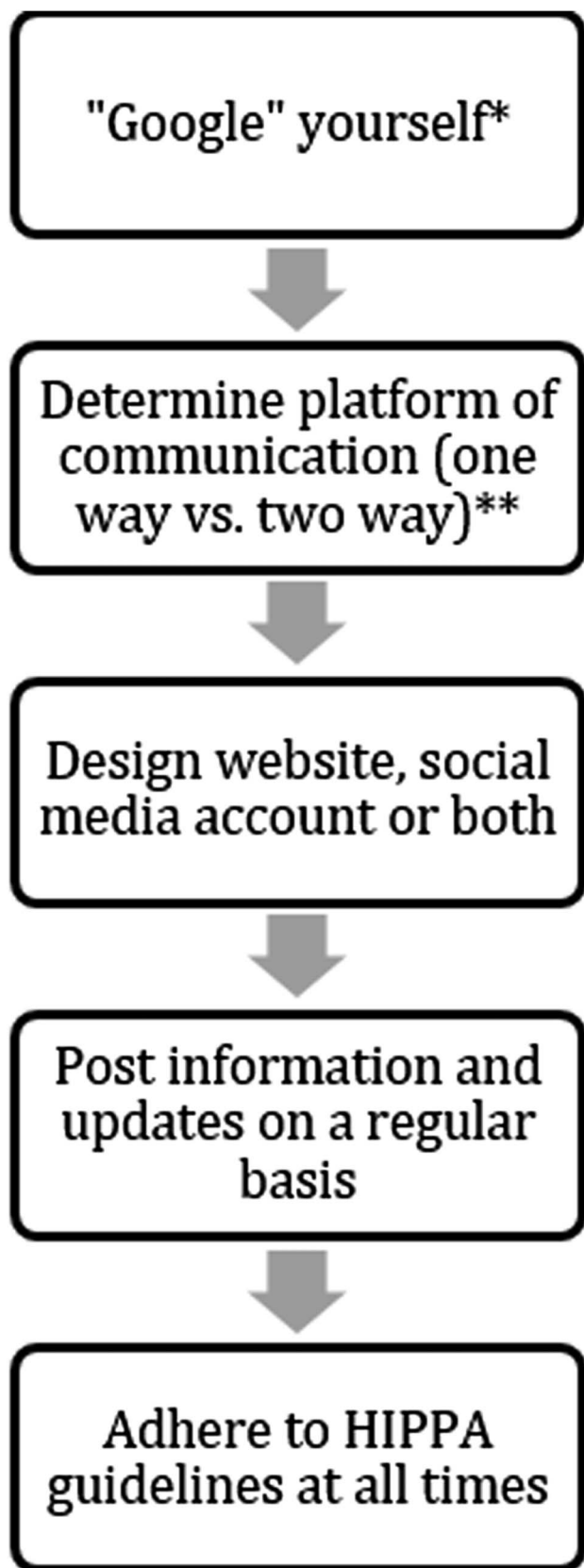
It is evident that both patients and providers are turning toward the internet and social media as a means of sharing health-related information. Patients clearly want to be able to interact with their health care providers in the digital world. Physicians may be reluctant to embrace social media as a means of providing patients with education given concerns about confidentiality and privacy. Physicians can use social media in an intelligent and safe manner. At our institution, we use EPIC as the electronic health record, which includes the patient portal called MyChart. MyChart is a product that allows patients to see components of their medical record and send and receive secure messages with their physician. Although evidence is limited to suggest that patient portals can improve disease outcomes, research suggests that for the most part patients are interested in using patient portals in the management of their disease.¹⁸ Incentive programs from Medicare and Medicaid have also been driving the use of patient portals. Our home institution (Boston Medical Center) is seeking to comply with patient engagement criteria of Centers for Medicaid and Medicare Services for meaningful use. Essentially, 5% of each Boston Medical Center physician’s patients must sign up for MyChart and 5% of patients must send a medically relevant message for providers to meet meaningful use criteria of Centers

for Medicaid and Medicare Services. Future research will need to address patient satisfaction, barriers to use, and impact on disease management with regard to the use of patient portals.

Carroll and Ramachandran¹⁹ published an article that describes how physicians can take advantage of digital tools and social media to enhance their practices and patient care. They argue that as internet and social media use is increasing among patients, providers must create their “digital footprint.” Providers and practices can start by creating a website. Before doing so, it is important to perform an internet search of oneself to get a sense of what information already exists about yourself online. Early on, providers must decide between a 1-way platform versus a 2-way platform of communication. A 1-way platform does not allow for communication between the patient and the provider (i.e., website, or blog), whereas a 2-way platform allows for back and forth communication i.e., (Twitter account, Facebook account). A social media account can be beneficial for a provider, as it can allow them to stay up to date with content, network with other physicians, and provide patient education for patients who exist outside their practice. This can foster the patient–provider relationship. They should post frequently and incorporate social media into their website. Finally, patient education should be the goal. Many risks are associated with having a presence online and in social media. It is crucial that physicians remain professional at all times. It is important that providers never use a personal account when communicating with patients. Physicians must be aware of HIPAA regulations regarding protected health information. Although communication with patients through patient portals such as MyChart are secure and may contain protected health information, communication through the Internet, email, and social media must not contain any information that could reveal a patient’s identity. Although a positive online footprint can certainly enhance a providers practice and patient interactions, a negative online footprint can lead to patient dissatisfaction (Fig. 1). At our home institution, a social media policy explicitly details how providers should use social media appropriately with relation to the hospital and its patients. Policy specifics include details on general behavior on social media sites, professionalism on social media sites, and representing Boston Medical Center on social media sites.²⁰

SOCIAL MEDIA USAGE IN OTHER CHRONIC MEDICAL CONDITIONS

Social media usage is prevalent in many chronic medical conditions. A survey published in 2011 sought to assess the preferred modality of communication to receive asthma information from their physician.²¹ The investigators found that email was the (70%) preferred method of communication to receive health-related information from their doctor. Forty percent of patients would be interested in receiving information through text messaging, and 30% of patients would be interested in receiving information through Facebook. Few patients had interest in receiving information through MySpace or Twitter. Anonymity was listed



as one of the main concerns for using social media sites to obtain health information.

Disler et al,²² 2015, sought to describe the patterns of technology use in patients attending a cardiopulmonary outpatient clinic. One hundred twenty-three patients were surveyed. Technological devices were widely prevalent in everyday life. Internet use was prevalent (104/121, 86.0%) as was social media use (71/121, 58.7%). Most (73.9%) of the patients reported that access to health support programs and assistance through the Internet would be of benefit. Concerns related to participating in an online environment included privacy, security, accuracy of information, and computer literacy and access. Most patients (78%) did not have concerns in partaking in online communications with health care providers. These studies highlight that patients are seeking to interact with providers through both the Internet and social media.

Greene et al,²³ 2011 evaluated the content of communication in Facebook groups dedicated to diabetes. They evaluated the 15 most recent wall posts and 15 most recent discussion topics from the 10 largest diabetes Facebook groups. Roughly two-thirds of the information posted included unsolicited sharing of diabetic management strategies. Almost 30% of posts featured 1 user providing emotional support for another member, and another 30% of posts were promotions for non-FDA-approved therapies. The authors note that inaccurate posts were infrequent, and usually associated with promotion of a product or service. The large number of posts promoting non-FDA-approved therapies serves as a reminder that providers must guide patients in the direction of evidence-based FDA-approved treatments.

Although social media sites such as Twitter and Facebook are widely used in health care, newer social media applications such as Instagram are also gaining popularity. Instagram is a smartphone application that allows users to share pictures among each other. Instagram has 300 million active users.²⁴ Karimkhani et al²⁵ conducted a search of dermatology related posts on Instagram. They found that most of the dermatology posts were dominated by private practices, patient advocacy groups, and cosmetic businesses. The top 10 dermatologic journals did not have a presence on Instagram. The authors note that Instagram could provide a novel medium for dermatologists to educate patients through various photographs related to dermatologic condition. We performed a search on Instagram using the “hashtag” IBD and found more than 160,000 IBD-related posts (March 25, 2015). Future research should examine the content, quality, and ownership of IBD related posts on Instagram.

Social media use has also been expanding in the infectious disease field. Scandell et al²⁶ reviewed Twitter posts that mentioned the word “antibiotics” to explore misuse and misinformation about antibiotics. They randomly selected 1000 status

FIGURE 1. Creating a digital footprint. *An internet search of oneself is important for identifying both positive and negative information that may exist about you online. **A 1-way platform of communication involves providers disseminating information to others, whereas a 2-way platform involves communication between 2 or more parties.

updates on Twitter. Roughly 30% of posts contained the combination “flu + antibiotics” and “cold + antibiotics.” Although this study is limited by inability to determine improper usage of antibiotics through social media, it does however suggest that medication misinformation may be prevalent on social media. Future research should examine the content and quality of IBD related posts on Twitter.

SOCIAL MEDIA USAGE AMONG PROVIDERS

Although social media usage has been increasing among patients, providers and hospitals are also embracing this digital platform to enhance patient care. Van Mierlo et al²⁷ examined gastroenterologists’ perceptions of mobile health tools for patients with IBD. In this small study, 4 of 7 gastroenterologists reported that patients had brought digital resources with them to an appointment. All gastroenterologists surveyed felt that digital tools could be used to save the time of office visits. All felt that inclusion of evidence-based facts was of greatest importance when designing digital applications. All gastroenterologists felt digital resources for patient-peer networks were important, but only if they were closely monitored by an expert. Although this study is limited in size, it suggests gastroenterologists are supportive of social media and mobile health technology for enhancing patient care.

Social media is not only used by physicians and patients but also by larger entities such as hospitals and large organizations. Richter et al²⁸ examined social media usage among hospitals and found that roughly 7 in 10 hospitals across the United States use social media. Social media usage was more likely to occur in hospitals that are in urban settings, are large nonprofit institutions, and are affiliated with universities. The authors found that most hospitals use social media to educate consumers, acknowledge staff, and share news regarding the hospitals awards. Yet, most hospitals did not engage with consumers on their Facebook pages. The authors suggest that the lack of engagement by hospitals with pages through their Facebook pages is a lost opportunity for patient education.

SOCIAL MEDIA USAGE IN PATIENTS WITH IBD

Internet usage among patients with IBD has been previously studied and revealed that patients frequently use the Internet to obtain health-related information.^{29,30} Less is known regarding social media usage and preferences in this patient population. A survey of GI specialists across the country sought to determine patterns of internet use in IBD physicians and their perceptions of how their patients use internet resources.³¹ Most (82%) of the physicians surveyed used an internet-based reference to help them decide clinical management strategies, including uptodate.com, pubmed.com, and Crohn’s and Colitis Foundation of America. However, 81% thought that there was inaccurate information online and that this led to greater time spent in the office. Sixty percent of physicians surveyed have referred patients to use the Internet. This study emphasizes the importance of creating physician-certified online resources.

In 2012, Fortinsky et al,³² published a review of the literature, online websites, and social media sources to assess current trends in internet usage among patients with IBD. They assessed which online IBD websites were frequented the most by patients using data from Google, Yahoo, and Bing. Patients were not directly asked about site preferences. The authors also searched Facebook, Twitter and YouTube to examine IBD-related activity. They note that the largest IBD-related Twitter account is “@Crohn’sDiseaseSN.” This account is followed by more than 2500 users and functions as a support network for patients with IBD. Other notable Twitter accounts include those owned by @DrGailSalganick (Dr. Gail Salganick, colorectal surgeon), @ibdmd (Dr. David Rubin, gastroenterologist at the University of Chicago), @ericbenchimol (Dr. Eric Benchimol, pediatric gastroenterologist). These accounts post tweets related to advances in the field of IBD.

Using Boston University’s Twitter Collection and Analysis Toolkit (see <http://www.bu.edu/com/research/bu-tcat/>), we applied several algorithms to sort through Twitter data that were collected from September through early October 2015 using the search terms “Crohn’s” and “Ulcerative Colitis.” This method of visualizing data allows one to see the flow of information across the online community. The cohashtag graph illustrates the mix and interconnection of topics related to IBD. This method of using a “hashtag” graph allows one to understand what is being communicated in the public space and how such conceptual interactions occur. In short, the Twitter Collection and Analysis Toolkit system creates network files suitable for the application of several algorithms that first spatialize network structures, then create size and color nodes based on specific features, such as centrality and communities of keywords. Sortable data files of computed network statistics are also produced as output.

In the application of this technique to IBD, there were 2457 tweets from 1646 users summarized into 569 hashtag nodes with 748 undirected edges. Our “hashtag” graph revealed that the most prominent hashtags among individuals discussing Crohn’s and ulcerative colitis were, “pain,” “cancer,” “depression,” “arthritis,” “autoimmune,” and “IBS,” as shown in the interactive online graph [that is available at <http://www.betweenness.org/colitis>](http://www.betweenness.org/colitis) (Fig. 2). AU7
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Although the Twitter Collection and Analysis Toolkit does not claim to capture all tweets that are shared, it does report a high level of representativeness of Twitter content more broadly speaking.^{33,34} Through this data collection system, future analyses can engage this technique in a similar fashion to identify the most influential posters on Twitter. Put somewhat briefly, the analytic approach outlined here can model not only what is being said in online social media spaces, but also which users are especially influential in those communities of users in directing both topics and tone.

Farmer et al,³⁵ 2009 conducted a search of Facebook for the most prevalent noncommunicable diseases as identified by the world health organization to identify whether they were represented among Facebook users and Facebook groups. They found that the groups with the most users were malignancies and

of patients surveyed were interested in responding to other patients questions and 51% were interested in discussing general IBD information. However, the actual usage was markedly lower with only 52% actually seeking out IBD information online and 14.3% visiting an IBD organization site. The discrepancy between interest in obtaining information and actual web-based usage necessitates further research. Although the Internet has a wealth of information, it can be difficult and daunting to parse out and find reliable and accurate information. Clinicians should work with the community to design patient friendly websites that cater to their needs.

Bernstein et al²⁹ investigated the information needs and preferences of newly diagnosed patients with IBD. They found that the most common sources of information among patients with IBD were their gastroenterologist and the Internet (36% versus 38%). They did not examine social media (Bernstein).

Rezailashkajani et al³⁰ created a web-based patient education system that provided general knowledge about ulcerative colitis and Crohn's disease. The website also included a forum where patients could interact with each other. The authors found that a web-based patient education site was favorable among patients and an effective means for educating patients given the busy time constraints in clinic.

Elkjaer et al³¹ conducted a randomized controlled trial to investigate the impact of web-based disease specific education versus the standard of care. Patients who were randomized to the web-group preferred the web-based approach compared with the standard education they received in clinic. Patients in the web-based group also had greater adherence to treatment, improved quality of life, fewer treatment relapses, and fewer clinic visits. This study suggests that patients are welcoming of a web-based platform as a component of disease management, and that this approach can save money.

Plevinsky and Greenley³² examined health-related quality of life and social functioning in adolescents with IBD who recently attended a disease-specific camp followed by participation in a postcamp Facebook group. Significant increases in HRQoL were seen postcamp compared with precamp, and post-Facebook group compared with postcamp. Improvements in social functioning were also seen postcamp and post-Facebook group. The authors note that the presence of an online community can enhance social functioning among adolescents with IBD. Further research needed in adult populations to see if online communities can enhance social functioning.

QUALITY OF IBD INFORMATION ON SOCIAL MEDIA

Because patients are increasingly using social media as part of their disease management, physicians must be aware of the range of quality of information that is posted. Bernard et al³³ sought to evaluate the quality of the top IBD websites on "Google" using the search terms "Crohn's Disease" and "Ulcerative Colitis." The authors used the quality evaluation instrument

(scale ranges from 0 to 107) and the 5-point global quality score. The median quality evaluation instrument score was 57 and the median global quality score score was 2. Although this study was limited by a small number of expert reviewers, it suggests improved quality websites are needed. To date, no studies have evaluated the quality of IBD-related posts on social media.

Promislow et al³⁴ assessed how well IBD-related websites answered patient's questions regarding their disease. Websites were evaluated using the DISCERN and the Ensuring Quality Information for Patients scales. The DISCERN scale consists of 15 questions that addresses the reliability of a publication, overall quality, and specific treatment details. The Ensuring Quality Information for Patients scale similarly consists of a 20-question scale that addresses issues related to the quality of patient information. They found that many websites lacked information on the prognosis of IBD, side effects of treatments, and the risk of developing cancer.

Van der Marel et al³⁵ also conducted a quality evaluation of IBD-related websites. Using the DISCERN, they rated 43% of sites as excellent to good and 57% of sites as fair to poor. Websites discussing alternative medicine scored significantly lower than other websites.

Cima et al³⁶ reported that 69% of IBD patients use the Internet as a way to gather information about their disease. This number has likely grown over the last half decade. On a scale of 0 to 10 (0 being the least trustworthy, with 10 being very trustworthy), patients rated IBD-specific information from the Internet at 6.8. Two-thirds of patients would prefer to communicate with their physician through email.

Mukewar et al, 2013, examined the 100 most viewed IBD-related videos on YouTube. They found that the overall patient education was poor. Videos were often anecdotal, and discussed alternative treatment options. Interestingly, videos discussing patient education received a higher number of "likes" compared with those discussing alternative treatment options.³⁴ These studies illustrate the need for clinicians to have a greater presence in the social media community, to improve the quality of information posted.

CONCLUSION AND AREAS OF FUTURE RESEARCH NEEDED

Our review has highlighted the increasing use of social media in chronic illnesses and in particular IBD. Over the last decade, there has been an increasing desire from patients to receive educational material regarding their illness through social media. There are financial implications to practices who can meet meaningful use targets by communicating with patients electronically. Providers of patients with IBD should be aware of the various sources patients use to obtain information about their illness. Unfortunately, the quality of medical information posted online varies greatly. We encourage physicians to have a presence online and in social media so that the quality of information posted online can be improved. Important areas for future research are suggested in Table 2.

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