Use of Social Media for Health-Related Tasks by Adolescents With Inflammatory Bowel Disease: A Step in the Pathway of Transition

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Background: Social media is commonly used among the adolescent and young adult population, including those with chronic diseases. For adults, these platforms have been shown to be a major source of health information. Our aims were to explore how youth with inflammatory bowel disease (IBD) use social media for (1) disease information gathering, (2) provider communication, (3) sense of belonging to the IBD community, (4) self-expression around IBD, and (5) disease management/monitoring.

Methods: An anonymous and voluntary survey was administered to IBD patients age 12 to 25 years at a single center over 4 months.

Results: Of 218 patients approached, there were 109 respondents. The mean age of the cohort (SD) was 18 (2.9) years, 65% were male, and 82% had Crohn's disease. Almost all patients accessed the Internet daily, but only 17% reported looking up information about IBD "always" or "often." Less than half (47%) turned to medical websites (WebMD or Crohn's and Colitis Foundation) for information. A small number (16%) connected with other IBD patients. Patients' preferred communication with provider was by e-mail (88%) compared with a phone call to the office (67%) or hospital website/patient portal (52%). Few patients used mobile applications to monitor symptoms (2%) or for medication reminders (9%), although there was professed interest.

Conclusions: Adolescents and young adults with IBD are less likely than adults to use social media for health-related activities. They prefer e-mail rather than oral communication between visits, and privacy seems to be less of a concern. Targeted education and skill building may be helpful for this transitioning population.

Key Words: social media, adolescents, young adults, teens, inflammatory bowel disease, disease management

INTRODUCTION

Access to social media and the Internet has expanded, with 74% of United States households having Internet access according to the most recent census data. This has led to increasing use of social media as a medical resource for patients with chronic illnesses over the last decade.¹ Social media has been defined as any online venue that allows users to network and share information and includes social networking sites (ie,

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Instagram, Facebook, and Twitter) and content communities (ie, Pinterest and YouTube).² In 2016, 78% of US Americans were reported to have a social media profile.³

Patients with chronic illness, including inflammatory bowel disease (IBD), do turn to Internet sources and social media for information. Some reports indicate that patients with chronic health issues prefer asking health professionals for information about diagnosis, medications, or other specialists but turn to peers through social media for emotional support or practical advice for coping or treating "everyday" health issues.⁴ Other studies report that the Internet is used by a majority of patients to seek information about their own chronic health conditions, such as IBD.⁵

During the adolescent and emerging adult years, the large number of patients with IBD diagnosed in childhood⁶ will need to learn health-related tasks that are required for successful transition to an adult provider. Attention has been paid to more traditional tasks such as medication adherence and carrying insurance cards. However, this new generation of patients navigate the world in a different way, including frequent use of social media. Our aim was to explore the patterns of social media use for young people with IBD. More specifically, we are interested in the preferences of social media and telecommunication to (1) gather information regarding their chronic condition, (2) communicate with providers, (3) record/

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manage symptoms, (4) form a sense of community related specifically to their IBD, (5) serve as a platform for self-expression around IBD. A clear understanding of patients' social media preferences may allow us to engage teens and young adults in promoting self-management, education, and accessing appropriate health care. These steps may help promote autonomy in these young patients with inflammatory bowel disease as they move toward the adult health care system. In the long term, this should improve patient outcome.

METHODS

Consecutive patients with IBD from 12 to 25 years of age who presented for outpatient biologic infusions at the Boston Children's Hospital Centers between December 2016 and March 2017 were invited to participate. Exclusion criteria were inability to fill out the survey due to lack of English language skills and significant developmental delay.

The survey was introduced by a letter indicating that participation was confidential and voluntary. The survey was de-identified by putting it in a blank sealed envelope that was coded with serial numbers and then collected by a member of the research team to ensure confidentiality and anonymity. The research coordinator and providers were unaware of the patients' answers or whether they had completed the survey.

The survey was written by IBD providers, adapted from a survey used for adult patients⁷ and pilot tested with both healthy college students and adolescent IBD patients. The surveys contained questions about various uses of social media, including (1) information gathering about the condition, (2) communication with providers, (3) recording/managing symptoms, (4) connecting to a community with same condition, and (5) personal expression regarding the condition. Please refer to Appendix 1 for the full survey.

Associations between demographics and social media usage were tested with Pearson's chi-square. Kappa was used to test agreement between parent and child social media usage. All tests were 2-tailed, and alpha was set at 0.05. Additional analysis was performed on patients who were younger (12 to 17 years old) and older (18 to 25 years old).

RESULTS

Demographics

Responses from 109 of 218 invited patients represent a 50% response rate. Responders were relatively evenly split between those younger than age 18 and those older than age 18 years. There was a predominance of patients with Crohn's disease (82%), and slightly over half of the respondents were male (65%) (Table 1). Nonresponders were similar, with 63% being male and 95% having Crohn's disease.

Almost all patients reported daily access to the Internet. Top devices were smartphones (95%) and laptops

(87%). Younger patients used the iPad more often than older patients (53% vs 30%, P = 0.02). The social media sites preferred by patients varied by age and sex. Older patients had a higher rate of using Facebook several times per day (60% vs 19%, P < 0.001). Males used YouTube more (49% vs 17%), and females used Pinterest more (8% vs 0%, P = 0.04). Duration of disease did not have an effect independent from age.

Information Gathering

Patients did not often look up information about their disease. Only 17% report "often" or "always" looking up aspects of IBD (Table 2). There was no significant difference in frequency of information gathering by sex or age group. Overall, 63% of patients used search engines (Google, Bing), whereas 38% used medical websites (Crohn's and Colitis Foundation, WebMD)

TABLE 1. Demographics of Responders to the IBDSocial Media Survey

	12–17 (n = 49)	18–25 (n = 60)	All (n = 109)
Age, y	No. (%)	No. (%)	No. (%)
Male sex, %	33 (67)	37 (63)	70 (65)
Crohn's	42 (86)	49 (82)	91 (83)
UC	5 (10)	11 (18)	16 (15)
Indeterminate/other	2 (4)	0 (0)	2 (2)
Daily access to any device	47 (96)	59 (98)	106 (97)
Smartphone	47 (96)	57 (95)	104 (95)
iPad	26 (53)*	18 (30)	44 (40)
Laptop	40 (82)	55 (92)	95 (87)
Desktop	19 (39)	23 (38)	42 (39)

TABLE 2. Patient-Reported Information Gathering About IBD (n = 102)

	No. (%)
Look everything up about IBD	4 (4)
Often look things up about IBD	13 (13)
Sometimes look things up about IBD	35 (34)
Rarely look things up about IBD	26 (25)
My doctor can let me know if there is something important I need to know about IBD	23 (23)
Not sure	1 (1)

*No statistically significant differences between male/female or younger/older.

for this purpose. Older patients were more likely than younger patients to access medical websites (47% vs 28%, P = 0.04).

Communication With Provider

Patients were most comfortable with e-mail communication (88%) compared with using a phone call to the office (67%), using a phone app (59%), or using a hospital website/ patient portal (52%) (Table 3). Older patients were more comfortable making a phone call to the office compared with younger patients (78% vs 58%, P = 0.03). In general, patients felt that their parents could comfortably communicate with the provider in a variety of ways, including phone call (98%), e-mail (98%), patient portal (62%), texting (53%), phone app (47%), and Facebook messaging (35%). Older patients felt that parents would find the patient portal difficult (40% vs 13%, P = 0.005).

Using the Internet for Self-expression and Community Related to IBD

The majority of patients were not connecting with others who have IBD through social media. Only 16% reported currently doing this, and another 14% reported interest in doing so soon. A large group (42%) was not interested in connecting with other individuals with IBD (Table 4). A wide variety of social media was used for connection among those reporting current use, with the most common platforms being Facebook (n = 19) and Instagram (n = 18), followed by Twitter (n = 12) and Snapchat (n = 8).

Very few patients (9%) reported using social media for self-expression, with the most popular formats being Instagram and Facebook. Of these, 75% reported doing so with a known identity rather than anonymously.

Using Online Application for Disease Management

A small percentage of youth with IBD reported currently using online applications for medication reminders (9%), to schedule visits (6%), or to track symptoms (2%). However, 31% to 41% reported that they would be interested in using the application for various tasks (Table 5).

DISCUSSION

Adolescents and young adults use social media on a frequent basis, but it is not clear whether those with chronic disease are interested in using these platforms for health-related activities. More traditional transition-related tasks have been studied but may not reflect the preferences of the digital native generation. This study is the largest to examine the social media platform preferences of adolescents and young adults with IBD in relation to information gathering, self-management and symptom monitoring, communication between patient and provider, connecting with an IBD community, and self-expression around IBD.⁸

Information Gathering Pertaining to IBD

We found that youth with IBD rarely use social media as a source of health care information regarding their chronic disease despite having daily access to the Internet via smartphones and laptops. This is in contrast to a Canadian study of 63 adolescents with IBD in 2001 that reported that 52% had used the Internet for information about their condition, though only 14% had visited an IBD organization site.⁹ The age of the patient may be a key factor in the use of medically appropriate sites. In our population, 28% of younger patients used a medical website compared with 47% of older patients.

Older patients who use the Internet for health-related information gathering are more likely to use medical websites such as the Crohn's and Colitis Foundation of America (crohnscolitisfoundation.org) and WebMD. The Crohn's and Colitis Foundation has been rated as one of the best websites for IBD information.¹⁰ Even when reputable websites are used, the information may not always answer typical patient concerns such as medication side effects, self-management, or prognosis.¹⁰ Most websites are written at a 9th–14th grade reading level, so they

Method	I Could Do This Comfortably, No. (%)	I Could Do This, but I Would Be Uncomfortable, No. (%)	I Have No Idea No. (%)
Phone call to the office	71 (67)	31 (29)	4 (4)
E-mail	90 (88)	7 (7)	5 (5)
Patient portal (hospital website)	53 (52)	20 (20)	29 (28)
Texting	46 (45)	32 (32)	24 (24)
Facebook messaging	24 (24)	40 (40)	36 (36)
Phone app for doc communication	60 (59)	16 (16)	25 (25)
Other?	0 (0)	5 (6)	74 (94)

*No statistically significant differences between male/female or younger/older.

may be quite difficult for the average adolescent or young adult patient.^{10, 11} Our findings are in keeping with studies of adults with IBD. One study noted that 54% use the Internet for information,⁵ and another reported that of patients using the web, 86% visited CCFA.⁷

Communication With Provider

We found that the youth in this study with IBD felt most comfortable using e-mail to reach providers (88%) but endorsed a wide variety of communication styles. Even phone calls were described as a comfortable option for communication, particularly by older youth. Patients also assumed that their parents would have similar patterns of ease with communication, with the exception of the portal. It is interesting to note that patients chose other communication options over the patient portal, despite the superior confidentiality, which may indicate that youth prioritize access and ease of use over privacy; this differs from a study by Reich et al., which noted privacy and confidentiality as the greatest barrier to social media use in older IBD patients.⁷

Communication between providers and patients with a chronic illness is an important influence on patients' health outcomes.² Mobile technology and new forms of communication have been shown to aid doctor-patient communication and health management.^{12–15} A recent study has demonstrated that patient disease-specific communication with their health care providers may improve health-related quality of life for pediatric patients with IBD.¹⁶ A descriptive research study among adults with IBD suggested that nonadherence is more frequent

TABLE 4. Patient Reports on Connecting With Others
Diagnosed With IBD via Social Media (n = 106)

	No. (%)
I do this already	17 (16)
I don't do this yet, but I would be very interested in doing it now	15 (14)
Sounds like something I might like in the future	21 (19)
Does not sound interesting to me	46 (42)
I don't know	5 (5)

when there is discordance between the patient and the physician.¹⁷ Adult IBD patients who call frequently are more likely to have refractory disease.¹⁸ E-mails are the preferred method of communication for adolescent IBD patients, but there is not yet enough literature to know if this mode can be utilized to improve patient adherence or health.

Community Building and Self-expression Related to IBD

Few patients were interested in the use of social media to connect with other patients. We found that Facebook, Instagram, and Twitter were the most popular mediums for connection among those patients who were interested, and sex-specific preferences were noted regarding differing social platforms.

A study by Plevinsky and Greenley examined the effects on adolescent IBD patients who attended a disease-specific camp (Camp Oasis) followed by participation in an 8-week postcamp Facebook group. They noted a significant increase in health-related quality of life postcamp and post–Facebook group, suggesting that the presence of an online community may enhance social functioning among adolescents with IBD.¹⁹ A study in the United Kingdom looked at the therapeutic utility of an online support group where content analysis performed on a sample of 1505 messages posted to the online support group revealed that, similar to face-to-face support groups, the online group offered patients the opportunity to utilize a variety of self-help mechanisms.²⁰ Additional research is warranted to see if online communities can enhance social functioning more generally among adolescents with IBD.

Using Online Applications for Disease Management

Our results show that although few adolescent IBD patients currently use online applications to help in the management of medication, scheduling visits, and tracking disease symptoms, they show some interest in an application that may help them with all of these mentioned activities. Patients would most prefer an application to remind them to schedule a visit and track their disease symptoms.

It is known that Internet-based sites and mobile applications can be used to track health-related activities.¹³ There has

TABLE 5. Patient Preference on Medication and Symptom Management via Telecommunication

	No Thanks, No. (%)	I Might Use This, No. (%)	I'd Like to Use This, No. (%)	I Already Use This, No. (%)
Remind me to take my medication	29 (27)	34 (31)	34 (31)	10 (9)
Remind me to schedule visit	16 (15)	40 (37)	45 (41)	6 (6)
Remind me to attend scheduled visit	16 (15)	38 (35)	40 (37)	12(11)
Help me track my symptoms	21 (20)	41 (38)	42 (39)	2 (2)

been a surge of health care applications¹³; more than 40,000 health care–related mobile applications are available in the market.¹⁴ Many patients are increasingly engaging with mobile health applications for self-monitoring.^{13, 21}

However, a reminder system such as an electronic monitoring device, phone, or pager text message does not seem to significantly impact adherence rates.²² A study on the effect of text messaging on medication adherence in children with IBD demonstrated an improved Morisky score in patients who received text message reminders about medication administration, although this was not shown to be statistically significant (P = 0.0131).²³

Our study demonstrates that young patients with IBD are interested in using an application to remind them to schedule visits and track disease activity, which may ultimately improve health outcomes and compliance in these chronically ill patients.

LIMITATIONS

Our study has important limitations. One limitation of this study may be that all patients were enrolled from our infusion center, which reflects either present or past moderate to severe disease activity. Therefore, this patient population may be more socialized to the medical system because of the severity of their disease. Because this is a single-center study, generalizability may be limited as this is specific to our referral patient population. An additional limitation includes social desirability bias as patients who fill out a survey may attempt to provide answers to our questions that they think are most appropriate. For example, a large percentage of patients reported being comfortable with calling the office, but that has not been common in the 20-year experience of the authors. Furthermore, in this particular sample, there happens to be a higher percentage of males than expected, which may not reflect the composition of the office population, creating sex bias.

CONCLUSIONS

Evaluation of self-management skills in the process of transitioning to adult medical care has often involved classic tasks. Our study recognizes the significant usage of social media in young adolescent and young adult IBD patients and the potential role that it can play in the management, education, mental health, and monitoring of their disease. It is clear that opportunities to engage adolescents and young adults with IBD exist using social media as a tool. However, the platforms for social media are diverse and continue to evolve, and, thus, additional research must be done to identify the most useful social media application(s) for these patients and how they may be used to educate and aid in their disease management through a safe, effective, and user-friendly interface.

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APPENDIX 1. SOCIAL MEDIA AND IBD

Please Tell Us A Little About You

	old are you now				
Are y	ou in middle school				
	High school				
	College				
	Not in school now				
Are y	ou Male Female				
Do yo	ou have (check one)				
	Crohn's				
	Ulcerative colitis				
	Indeterminate colitis				
	Other				
	Don't know				
Have	you had major surgery (removal of a	portion of the small intestine o	or colon)?Ye	sNo	
How	old were you when you were diagnose	ed with IBD?			
Doyo	ou have daily access to the Internet or Smartphone/mobile device iPad Laptop Desktop computer	The following devices (check at	i tilat apply).		
	- Change 1				
How	often do you use each of the followin	g?			
How	Several Times per Day	g? At Least Once a Day	1–2/wk	Rarely	Never
How	-		1–2/wk	Rarely	Never
nstagram	-		1–2/wk	Rarely	Never
	-		1–2/wk	Rarely	Never
nstagram witter ouTube	-		1–2/wk	Rarely	Never
istagram witter ouTube interest	-		1–2/wk	Rarely	Never
nstagram witter ouTube interest imblr	-		1–2/wk	Rarely	Never
nstagram witter	-		1–2/wk	Rarely	Never

Is there any other social media that you use frequently?

Getting Information About Your IBD

Many people like to look up information about their condition or medications, whereas others prefer not to do that. Put a check next to the statement that sounds most like you.

____I look everything up about IBD

_____I often look things up about IBD

_____Sometimes I look things up about IBD

_____I rarely look things up about IBD

_____My doctor can let me know if there is something important I need to know about IBD

____Not sure

If you DID want to look up information (symptoms, medication, surgery, etc.), where would you look? Put one check for your best guess about each social media option

	I Currently Use This	I Would Use This	I Would Not Use This	I Have No Idea
Google (or other search engines like Bing)				
Medical websites (CCFA, Web MD, etc.)				
YouTube				
Instagram				
Twitter				
Facebook				
Reddit				
Other				

Communicating With Providers

If a problem comes up between office visits, one option is to call your provider to discuss it or to ask questions. If you had a problem or question and needed to contact your provider, which would you prefer to use IF IT WERE AVAILABLE to you?

Method	I Could Do This Comfortably	I Could Do This, but I Would Be Uncomfortable	I Have No Idea
Phone call to the office			
E-mail			
Patient portal (hospital website)			
Texting			
Facebook messaging			
Phone app for doc communication			
Other?			

Now think about your parents—what would they be able to use to contact providers if there was a problem? Take your best guess about what you think they could do

I Could See My Parents Doing This Without Too Much Trouble	My Parents Could Do This, but it Would Be Difficult for Them	I Have No Idea
	, 6	

Are there other ways you might like to contact your provider between visits?

Connecting With Others

Many people use social media to connect with others who have the same conditions. This can be reading someone's story, asking questions of each other, getting ideas of how to do things better, getting encouragement, or having others listen who "know what I'm going through."

Put a check next to the statement that is closest to what you feel.

____I do this already

_____I don't do this yet, but I would be very interested in doing it now

_____Sounds like something I might like in the future

____Does not sound interesting to me

____I don't know

If you DID want to connect with others who have IBD, which of the following would you be likely to use? Put a check in each row for your best guess about each option

	I Currently Use This	I Would Use This in the Future	I Would Not Use This	I Have No Idea
Instagram				
Twitter				
YouTube				
Pinterest				
Tumblr				
Facebook				
Reddit				
Snapchat				
Other?				

Managing a Condition

It can be helpful to use electronic reminders for medication or an online application to track symptoms. How likely would you be to use an app that helped with the following?

	No Thanks	I Might Use This	I'd Like to Use This	I Already Use This
Remind me to take medicine				
Remind me to schedule a visit				
Remind me to attend a scheduled visit				
Help me to track my symptoms				

How else could an app help you manage your IBD?

What do you think about using apps for tracking or managing your IBD?

Are there any apps related to IBD that you have heard of, looked at, or used at all? (please list) Were they helpful?

Sharing on Social Media

Many people use social media to post, talk, or write about what is happening in their lives.

Do you use any of the following to write or post about your IBD? Put a check next to those you use for this purpose

-	
	_Instagram
	_YouTube
	_Facebook
	_Pinterest
	_Tumblr
	_Twitter
	_Whatsapp
	_Reddit
	_Blog
	_Online forums

If you share information, do you share your identity ______ or share anonymously? _____

Comments

We are always interested in what our patients are thinking and doing. Do you have other thoughts about social media and how it can be useful or not useful for patients with IBD?

Anything else you would like us to know?

Thank you!