


Motivations for Participation in an Online Social Media Community for Diabetes

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Abstract

Background: Our objectives were to describe individuals' motivations for participation in an online social media community and to assess their level of trust in medical information provided by medical professionals and community members.

Methods: A purposive survey was delivered to participants recruited through posts on the CGM in the Cloud group, Twitter, and blogs. Individuals were asked a series of demographic and social media use questions.

Results: A total of 1268 members of the CGM in the Cloud community responded to the survey. The majority were non-Hispanic White (92.1%) and caregivers of an individual with diabetes (80.9%). Mean age was 41 years old, and 74.8% were female. Primary goals of the Facebook group were to learn more about Nightscout technology and to receive technological assistance. Individuals provided assistance to the community through spreading awareness, technical assistance, support, and donation. Respondents put a high level of trust in their peers versus health professionals in many health situations with nearly 40% of individuals reported to be helped by following advice found in the Facebook group, and 99% reported no harm.

Conclusions: Our findings suggest that patients with diabetes and their caregivers use social media for many health-related purposes including medical recommendations and technical support for medical devices and systems as well as emotional support.

Keywords

type 1 diabetes, mobile technology, online community, social media

A majority of US adults (69%) use some form of social media; therefore, it is not surprising that individuals are increasingly turning to social media to share and seek health information.^{1,2} The Pew Research Center has reported that as many as one in four internet users living with a chronic health condition go online to find others with similar health concerns.³ There is a robust online community of individuals affected by diabetes who are communicating via the Internet,⁴ including community forums that were specifically designed for providing support to the diabetes community, as well as communities that have organically congregated on social media platforms such as Facebook and Twitter.⁵

CGM in the Cloud is a private Facebook group that was originally created in 2014 with the purpose of sharing information about Nightscout, a do-it-yourself (DIY) mobile technology system for remotely displaying blood glucose values from a continuous glucose monitoring (CGM) system. The original computer code for Nightscout was developed by the father of a four-year-old boy with type 1 diabetes who hacked into his son's FDA-approved CGM, to upload

glucose values to the Internet through an Android phone, providing real-time access to blood glucose data on web-based, mobile, and wearable applications. He shared his code with a community of other interested individuals which led to the creation of the Nightscout project, an informational website (<http://www.nightscout.info/>) with instructions and links to the open source code, as well as the formation of the CGM in the Cloud private Facebook group, permitting

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dissemination of the technology tools to a larger diabetes community. The group started with just 40 members in 2014; as of August 2017, the group has over 24 000 members and is one of the largest type 1 diabetes communities on Facebook.

The CGM in the Cloud community provides a unique opportunity for understanding how patients and caregivers are using social media for health. We therefore conducted an anonymous online survey of the community in the summer of 2015. Our objectives were (1) to describe the community members' motivations for participation in the social media group, and (2) to assess the level of trust in medical information provided by medical professionals and community members.

Methods

As described in a previous publication,⁶ we conducted a purposive survey of individuals who were recruited through posts on the CGM in the Cloud Facebook group, Twitter, and blogs. Between June and August of 2015, 1461 individuals completed an electronic, web-based survey created and distributed through Qualtrics survey software. Participation in the survey was anonymous, voluntary, and limited to adults over 18 years of age. Individuals under age 18 were asked to have a parent/guardian complete the survey. Respondents were asked to complete only a single survey per household. No financial compensation for participation was provided. The Institutional Review Board of the University of Michigan Medical School deemed this study exempt.

After excluding 193 respondents who reported that they were not members of the CGM in the Cloud Facebook group, the remaining 1268 respondents were asked a series of questions on community member demographics as well as types of Nightscout and online community use. The 140 questions (see supplementary material) were developed with input from patient partners in the CGM in the Cloud community and piloted with a small number of users in two iterations before final release.

We surveyed individuals about demographic characteristics and the average daily time spent on the group. Individuals were asked about the motivations for accessing this online community: (1) to learn more about diabetes in general, (2) to learn about Nightscout, (3) to share information about diabetes and/or diabetes technology, (4) to give technical assistance to other individuals using Nightscout, (5) to receive technical assistance from other individuals using Nightscout, (6) to give emotional support for diabetes, and (7) to receive emotional support for diabetes. For each of these questions, respondents could choose one of the following responses: not at all likely, a little likely, somewhat likely, very likely, or extremely likely.

We also asked whether the individual or their household had helped others in the CGM in the Cloud community by "paying it forward," a term created by the community that

we defined as providing diabetes-related support to someone else in the community. If the answer was "yes," we asked them to describe what type of contributions they had made. We also asked if individuals had met anyone from the CGM in the Cloud community in person because of a connection through the Facebook group. We delivered a survey instrument used by the Pew Research Center's Internet & American Life Project to understand trust in different types of health information provided by professional sources like doctors or nurses, and fellow patients, friends, and family.³ Finally, we inquired whether individuals had been helped or harmed by following medical advice or health information provided in the CGM in the Cloud Facebook group.

As described in a previous publication,⁶ because the survey was long (averaging 140 questions), a moderate number of respondents did not complete all of the questions. As participation in the survey was voluntary and some topics could be considered potentially sensitive, respondents were permitted to skip any question, resulting in item nonresponse in the study. Demographic questions were not asked of 318 respondents who did not complete the entire survey since these questions were the final survey items. We report the frequency of missing data as the Unknown category in Table 1; we therefore conducted analyses according to the available responses to a given item. All descriptive analyses were performed using Stata/SE 13.

Results

Of the 1268 respondents who were members of CGM in the Cloud community, the mean age was 41 years and 74.8% were female (Table 1). The majority were non-Hispanic White (92.1%) and most reported being either caregivers or parents/guardians of an individual with diabetes (80.9%). Most were highly educated individuals with an associate's degree or higher (84.0%). More than half of individuals were from the United States (78.0%). The majority of individuals reported hearing about the CGM in the Cloud community via Facebook (59.4%), followed by friends (16.3%). Few heard about the community from their health care providers (3.7%). Most individuals reported using the Facebook group less than one hour per day (85.2%), with 9.1% reporting using it for one hour or more per day and 5.7% selected "other" under minutes per day.

The majority of respondents reported that they were very or extremely likely to use CGM in the Cloud to learn more about Nightscout (88.9%), to learn more about the latest technology in diabetes (79.6%), and to receive technical assistance from others using Nightscout (62.8%, Figure 1). A majority of individuals (53.2%) also indicated that they were very or extremely likely to share general information about diabetes and/or technology in the Facebook group. Fewer individuals were using the group to give (45.3%) or receive emotional support (37.3%), to learn more about diabetes in general (37.3%), or to give technical assistance to others

Table 1. Characteristics of Survey Respondents Who Are Members of CGM in the Cloud, Representing One Household.

Characteristics	Members of CGM in the Cloud (N = 1268)
Sex	
Female	711 (74.8)
Male	237 (24.9)
Other	2 (0.2)
Unknown ^b	318
Race	
White non-Hispanic	854 (92.1)
Hispanic or Latino	26 (2.8)
Asian	10 (1.1)
Black/African American	5 (0.5)
Native Hawaiian/Pacific Islander	2 (0.2)
American Indian/Alaskan Native	0 (0.0)
Other	30 (3.2)
Unknown or Do not wish to provide ^b	341
Relationship to diabetes^a	
The caregiver/parent/guardian of an individual with diabetes	1026 (80.9)
An individual with diabetes	242 (19.1)
A relative of an individual with diabetes	110 (8.7)
A friend of an individual with diabetes	61 (4.8)
Someone who works in the area of diabetes	54 (4.3)
A spouse/significant other of an individual with diabetes	53 (4.2)
Other	2 (0.2)
Education	
Master's, professional, doctorate degree	313 (33.8)
Associate's or bachelor's degree	465 (50.2)
High school/GED	143 (15.4)
Less than high school diploma/GED	6 (0.6)
Unknown or Do not wish to provide ^b	341
Residence	
United States	720 (78.0)
Outside of the United States	203 (22.0)
Unknown ^b	345
First hear about CGM in the Cloud Facebook Group	
Social media through Facebook	748 (59.4)
Friend	205 (16.3)
Other web/social media	81 (6.4)
Social media through blog posts	64 (5.1)
Health care provider	46 (3.7)
Family	45 (3.6)
Social media through Twitter	30 (2.4)
Traditional media (article in the newspaper, or news on TV or the radio)	16 (1.3)
Other	14 (1.1)
Conference	11 (0.9)
Unknown ^b	8
Minutes per day spent on the CGM in the Cloud Facebook Group	
0 to less than 10 minutes	767 (60.5)
10 to 59 minutes	313 (24.7)
1 hour or more	116 (9.1)
Other	72 (5.7)

Values are numbers (percentages).

^aResponses were not mutually exclusive.

^bThe amount of missing data is reported, but analyses were only among complete cases.

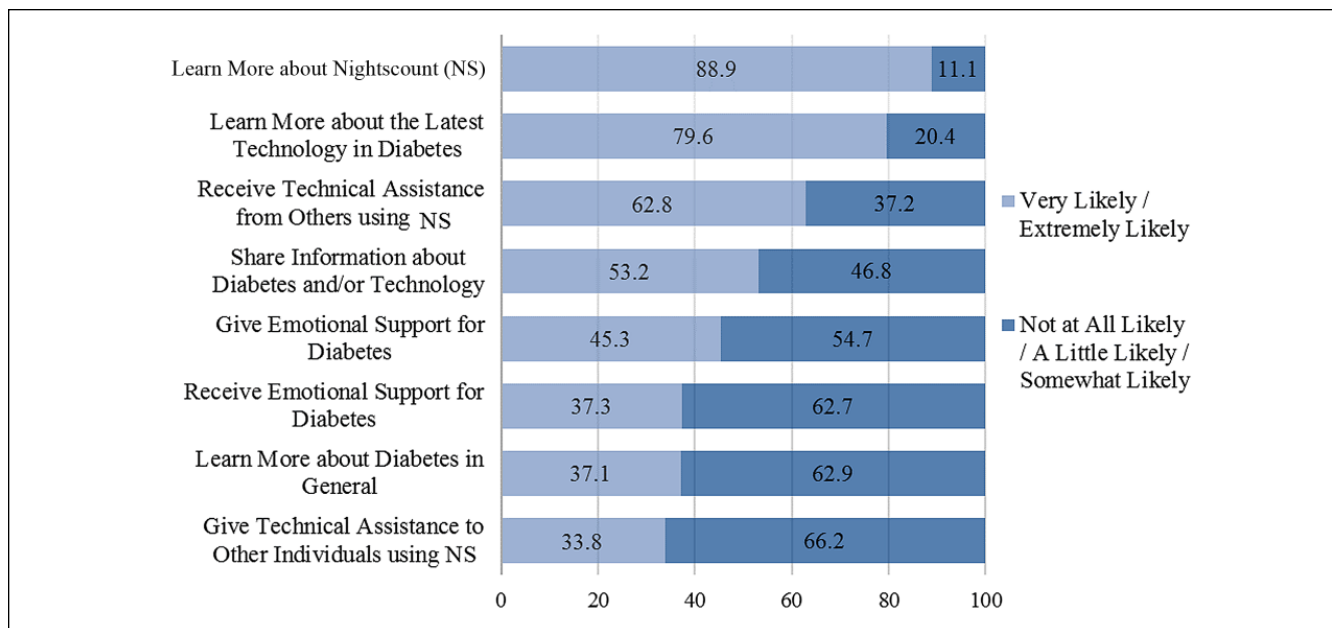


Figure 1. Reported likelihood of members to use CGM in the Cloud Facebook group for technical, emotional, and general support.

using Nightscout (33.8%). The reported likelihood by each response category is further described in the supplementary figure.

Table 2 provides further descriptions from respondents regarding how they provided diabetes-related assistance to others in the community by “paying it forward” (n = 197). We reviewed all responses, which fell into the categories of spreading awareness, technical assistance, support, and donations. Nearly one-fifth (19.0%) of the 1268 CGM in the Cloud survey respondents indicated they met someone in person that they hadn’t met before because of a connection made through the Facebook group.

Table 3 provides preference information for trusted sources about health. The majority of individuals were much more likely to trust professional sources like doctors and nurses regarding information about prescription drugs (58%), but were far more likely to trust fellow patients, friends, and family members when looking for emotional support (79%), a quick remedy for an everyday health issue (71%), practical advice for coping with day-to-day health situations (69%), and information about alternative treatments (51%). Both professional sources and fellow patients, friends, and family were equally trusted for recommendations for doctors or specialists or for hospitals or other medical facilities.

Nearly 40% of individuals reported being helped by following medical advice or health information found on the Facebook group (n = 482). Only one individual reported suffering harm from following medical advice or health information from the CGM in the Cloud Facebook group. However, their description characterized the harm as being related to having access to “too much information about blood sugars.”

Discussion

This study of an online diabetes community on Facebook provides insights into how patients with diabetes and their caregivers use social media for health-related purposes. The group was originally formed to provide an online forum for a DIY diabetes remote monitoring system which no doubt shaped the nature of the participation in the group. The group’s rapid growth in membership and level of participation by members revealed a novel motivation for social media communication in health: learning about DIY technologies developed by patients and caregivers, giving and receiving technical assistance to individuals, and exchanging information about diabetes technology.

In addition to the technology focus, individuals also used the group for giving and receiving information and emotional support, which is consistent with previous literature about diabetes online communities.^{4,7} Greene et al conducted a qualitative content analysis of Facebook posts from the 15 largest Facebook groups focused on diabetes management and reported that information sharing was the most common category (65.7%), followed by support (28.8%), advertisements (26.7%), and information requests (13.3%).⁷ Another small study of parents of children with type 1 diabetes (n = 100) reported that they participate in diabetes forums for knowledge (74.5%) and social support (57.8%).⁸

Another novel finding from this study is that a subset of individuals were motivated to participate in the community for the purpose of making contributions in many forms, whether informational, technical, emotional, or even financial. Studies from the computing literature have highlighted altruism as a motivation for participation in

Table 2. Sample Contributions of Members From the CGM in the Cloud Community.

Category	Sample response
Awareness	
Spreading awareness to providers	“Local education with diabetes educators; ongoing education with nurses I work with.” “Educating hospital staff when daughter hospitalized.”
Spreading awareness to patients	“Spreading information to anyone I know or meet that is dealing with Type 1.” “Informing others in our local T1 group about Nightscout.”
Technical assistance	
Design	“Active beta tester for Medtronic uploader (with two CCIIII sticks).” “Experimenting with different NightScout cases in the early days and publishing my findings. More recently, I have been working on different xDrip device and uploader configurations.”
Setup	“Helped a single mother get set up with Nightscout. Did everything, as she was computer illiterate.” “Setting up nightscout and building xdrips for others.”
Troubleshooting	“Many hours of over the phone assistance.” “Support on dexdrip hardware.”
General support	
Emotional	“Providing encouragement and empathy.” “Hopefully, encouraging others who are afraid to attempt setup is considered ‘helping.’ Not technically savvy, I am the biggest cheerleader!”
Informational	“Providing links to a doctor’s sick day video and other links related to insurance (Medicaid) issues for CGM coverage.” “Locating and posting helpful information.”
Donation	
Monetary	“Donation to Nightscout Foundation.” “Purchased Nightscout car stickers (donation to help Nightscout).”
Hardware	“Giving electronic equipment to other nightscout user.” “Bought a set-up for a new family (MotoG, cord, Ting account for 6 months).”

online communities, but this is one of the first to document this in the diabetes literature.⁹

The majority of our CGM in the Cloud survey respondents were female caregivers, consistent with past diabetes community studies^{1,8} and previous research suggesting that mothers primarily take part in child illness management.^{10,11} This may also be due to the fact that women use Facebook at higher rates than men.¹² The majority of survey respondents were also White non-Hispanic, and highly educated, which is consistent with national data suggesting that social media use is more prevalent among individuals who are highly educated.¹³

Regarding the time spent by users on social media for health-related purposes, our statistics may be difficult to compare with previous studies. For example, one small study of diabetes forum users found that 90.2% reported spending 30 minutes or more per week using T1D forums.⁸ The majority of users in our study responded that they spent less than 10 minutes on the CGM in the Cloud Facebook group per day (60.5%), but this may not represent all of their diabetes-related social media use beyond the Facebook group. Furthermore, we recognize our results may have been skewed by the disproportionate amount of time individuals spend on CGM in the Cloud when they are first setting up the Nightscout system and that this likely has changed as

enterprise mobile applications for viewing blood sugars have arrived to the marketplace.

Regarding trust in health advice, when we compare our findings about trust among the CGM in the Cloud community to a representative sample of adult individuals (N = 3001) from the Pew Research Center’s Internet & American Life Project, we find similar trends. In both studies, individuals put more trust in doctors and other health professionals compared with fellow patients, friends, and family members for information about prescription drugs, but put more trust in fellow patients, friends, and family members compared with health professionals for emotional support. However, we do note that these preferences were more pronounced for the CGM in the Cloud diabetes community. For instance, only 24% of Pew respondents versus 51% of our respondents indicated they would turn to peers for information about alternative treatments; 59% of Pew respondents versus 71% of our survey respondents said they would consult nonprofessionals when in need of emotional support. This discrepancy may be explained by the nature of diabetes as a primarily self-managed disease which requires more patient autonomy. We also recognize that our population chose to participate in an online community and utilize DIY technology, making them, perhaps, more motivated to consult nonprofessionals for health support than the general population.

Table 3. Sources That Patients Most Trust in Situations.

	CGM in the Cloud members (N = 1268), % (n)				Pew Research Center's American Life Project respondents (N = 3001), %		
	Professional sources like doctors and nurses	Fellow patients, friends, and family	Both equally	No response	Professional sources like doctors and nurses	Fellow patients, friends, and family	Both equally
Information about prescription drugs	58% (657)	7% (82)	35% (394)	(135)	85%	9%	3%
Information about alternative treatments	15% (164)	51% (573)	34% (384)	(147)	63%	24%	5%
A recommendation for a doctor or specialist	17% (187)	41% (468)	42% (476)	(137)	62%	27%	6%
A recommendation for a hospital or other medical facility	19% (218)	36% (401)	45% (506)	(143)	62%	27%	6%
Emotional support in dealing with a health issue	2% (28)	79% (893)	19% (214)	(133)	30%	59%	5%
A quick remedy for an everyday health issue	7% (76)	71% (799)	23% (257)	(136)	41%	51%	4%
Practical advice for coping with day-to-day health situations	4% (45)	69% (781)	27% (308)	(134)	43%	46%	6%

We acknowledge that the significant amount of trust that online community participants put in nonprofessionals could be cause for concern as there is potential for the posting of biased or low-quality information. However, 99% of the individuals surveyed suffered no harm from following advice from the group, with nearly 40% indicating they had actually been helped. This is consistent with recent findings in the literature. Cole et al had physicians assess diabetes and other disease information from online forums, reporting that the majority of information was reasonably high quality, with only a small proportion considered to be factually incorrect or potentially harmful.¹⁴ Further qualitative and quantitative study of communications inside the Facebook group are needed to study the accuracy and trustworthiness of the information, but the results from our study demonstrate positive outcomes in using social media as a community for chronic disease management, and without evidence of serious harm.

Although previous studies have focused on the role of social media in peer-to-peer health information exchange, they have been limited by smaller sample sizes or a lack of diversity,^{8,15-17} or observation of social media communities without direct outreach to patients and caregivers.⁴ We do however acknowledge limitations of our study. First, this was a cross-sectional study which relied on self-report of motivations for social media use. As studies have shown, participants' stated reasons for participating may be different than their actual intentions.¹⁸ Second, we did not have a representative sample of the community; respondents of the

survey may be different than those who chose not to respond. Third, CGM in the Cloud users may be more motivated to search for and give health support on Facebook compared with individuals from the general diabetes population as they have already proactively built their own DIY remote monitoring system. Fourth, because a DIY technology invention was the original focus for the group, it may be different from other online communities such as DiabetesMine,¹⁹ Children with Diabetes,²⁰ or Tudiabetes.²¹ Fifth, we must acknowledge that this represents a snapshot of the community at one point in time; the community has grown in size and purpose since the original survey so motivations of the population may have changed over time.

We report on the motivations of a novel online community engaged in social media communications. Our research group is in the process of conducting analyses of raw data from the Facebook group to further explore, in depth, the types of communications, the prevalence of the communications, and the evolution of conversations in the community since its inception. This will be pertinent in examining the structure and impact of this large diabetes online community.

Abbreviations

CGM, continuous glucose monitor; FDA, Food and Drug Administration; T1D, type 1 diabetes.

Declaration of Conflicting Interests

The author(s) declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this

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Supplementary Material

Supplementary material for this article is available online

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