

Should Patients with Diabetes Be Encouraged to Integrate Social Media into Their Care Plan?

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Abstract

Objective: The aim of this study was to evaluate use of social media of individuals with diabetes mellitus (DM).

Methods: Both web-based and in-clinic surveys were collected from individuals with DM. Questions included reasons for visiting the website, and ascertainment of DM reported self-care practices. Descriptive and correlation analyses were employed to evaluate respondents' diabetes-specific social networking site usage behaviors.

Results: Forty-five patients with DM completed the web-based survey and 167 the clinic based survey, of whom only 40 visited diabetes-specific social networking sites. Respondents most often visited sites to offer support for DM or to seek such support for themselves. Analysis of on-line survey data indicated that self-reported adherence to lifestyle recommendations was significantly correlated ($P<0.01$) with visiting the sites. Clinic based survey data found that patients who reported using DM-specific web sites monitored home glucose values more often and had better compliance with insulin administration (both $P<0.05$) compared to non-users.

Conclusions: Results of this study provided insight into why individuals visit DM-specific social networking sites. Certain self-management behaviors may improve the lifestyle. Further work is needed to explore how to incorporate DM social media use into the clinic environment and how to leverage the technology to assist patients with their disease.

Lay abstract

Social media has gained prominence as a source for health care information. This study used both on-line surveys and surveys of clinic patients with diabetes to understand why patients with diabetes use DM-specific social networking sites. The authors found that patients go to these resources to both offer and receive encouragement for their health condition. Visiting DM-specific social networking sites influenced more positive diabetes care behaviors, such as adhering to diet and exercise, glucose monitoring, and insulin use. Further research is needed to understand how to incorporate social media into care of diabetes.

Introduction

Social media is becoming an important resource for health care information [1]. Based on survey of 2008 U.S. adults, 87% used the internet to access information online [2]. Widespread access to the internet has made it relatively easy for people to go online to seek answers to their health-related questions. It is estimated that in the U.S. health information is sought online by 79% of Internet users. Moreover, the percentage of users that use the Internet as a source of health information rapidly increased from 38% of users in 1998 to 79% in 2011 [3, 4]. In addition, many patients use the Internet to find and join communities of individuals with similar health conditions, to share information, as well as to provide and receive support for health care management [5, 6].

Diabetes mellitus (DM) is a chronic illness that can be effectively managed through physical activity, healthy dietary habits, and the appropriate and timely use of pharmacotherapies to lower blood glucose levels [7]. Research has demonstrated that online social support programs like health care forums and social media websites (e.g. Facebook and Twitter) can help patients with type 1 DM on insulin pump therapy gain knowledge about their disease and cope better with their daily management routine [8]. Such platforms can allow patients to share personal clinical information, request diabetes-specific advice, and receive the emotional support that they need for diabetes management and self-care [9].

Most of the research on the influence of social media on DM care has focused on widely used platforms without a clear focus on a specific health condition [8, 9, 10]. Research has shown that such generic social media platforms have lots of promotional activity and personal data collection but no checks for authenticity [8]. On the other hand, most of the DM-specific social networking sites are moderated and enforce measures on patient privacy [9]. Often

moderated platforms ensure authenticity and correctness in the information delivered to users. Another study of preferences for online DM support found that adults generally preferred professionally moderated discussions [11]. Nonetheless, there remains a paucity of data on how patients with DM use social media or how it may impact their behaviors. Therefore, internet and clinic based surveys were conducted of patients with DM to assess the reason individuals visited DM-specific social networking sites and what impact such use had on specific self-management behaviors.

Methods

Data collection

Information regarding DM was collected through surveys. As part of the survey, participants were asked to answer questions broadly classified as 1) demographic information, 2) educational level, 3) marital status, 4) diabetes specific information (e.g., diabetes diagnosis, most recent hemoglobin A1c value), 5) nature and frequency of diabetes-specific social networking site usage, 6) dietary habits and diabetes self-care activities, and 7) reasons for using the site [12]. The surveys were collected in two modalities: 1) Anonymous, web-based survey and 2) from the patients at an in-clinic setting. The diabetes-specific social networking site questions are provided in Figure 1.

Both the web-based and clinic surveys were convenience samples. The web-based survey data were collected through a self-administered Qualtrics platform, advertised through DM-specific social networking sites (see Figure 1 for list of sites). Participation was anonymous and required individuals to be at least 18 years old. The clinic based survey was offered to all patients with DM returning for a follow-up appointment to an outpatient academic endocrinology practice in the Southwest United States. Once individuals read a brief consent document and

agreed to participate, they proceeded with the self-completed paper survey. No compensation was offered for participation. Questions on the clinic survey were identical to the web based version, except formatting was adjusted to accommodate the flow of the outpatient setting (Figure 1). Additionally, the clinic based survey incorporated chart review to obtain accurate information on medications, most recent hemoglobin A1c (HbA1c) value, and body mass index. A question on self-reported income range was added as well. The study was approved by the Institutional Review Boards of the participating institutions.

Data analysis

The demographic, DM-specific and social media usage information were analyzed using descriptive statistics. Associations between the use of DM-specific social networking website and DM-related behaviors were analyzed using correlation analysis with Pearson's correlation coefficient for analysis of the on-line survey [13]. The responses to the survey questions on DM-specific social networking sites usage contain both ordinal and categorical Likert scale [14] based responses. For convenience, the categorical responses were converted into a numerical scale with order and rank preserved. Questions and their responses were assumed independent of each other. For the clinic based surveys, differences between social media users and non-users were evaluated via *t*-test for continuous variables and χ^2 for categorical variables.

Results

Respondent characteristics

A total of 45 participants from the United States (N= 31) and United Kingdom (N=14) combined submitted their responses to the web-based survey (Table 1). Mean (SD) age was 57 (14) years, most were women, identified themselves as white, had attended college, and were not

working. The participant pool consisted of a balanced mix of patients who reported they had type 1 DM and type 2 DM. The mean (SD) self-reported hemoglobin A1c was 7.0 (2.2) %.

Between December 2016 and March 2017, 167 patients with DM participated in the clinic survey (Table 2). Of these, 40 (31%) indicated they used DM-specific social networking sites. Social media users were significantly younger than non-users ($P < 0.01$). Additionally, in this clinic sample, a significant difference in the distribution of diabetes type was detected ($P = 0.034$) between users and non-users. Within both groups, more patients with type 2 DM than type 1 DM used DM-specific social networking sites. However, between groups, the proportion of patients with type 1 DM who were users (33%) was higher than non-users (14%), while the percentage of those with type 2 DM that were non-users (82%) was greater than users (65%). Marital status was also different ($P = 0.017$), with a greater proportion of users indicating they were not married, while more non-users reported they were married. The distribution of employment status was dissimilar ($P = 0.016$), with more social media users working, while a greater proportion of non-users were not currently working. No differences in race/ethnicity, self-reported diabetes duration, insulin use, hemoglobin A1c, body mass index, education, or income level were found.

Website usage

The authors were interested in the distribution of why survey respondents went to DM-specific social networking sites. It was assumed that the two reasons social media users may go to sites are to either offer advice or support, or to seek advice or support. For this analysis, data from the on-line and clinic based surveys were combined, and considered individuals who frequently (at least 2-3 times a week) logged into the DM-specific social networking sites and analyzed the frequency of reasons for both offering and seeking information (derived from

Question 15). The two most common reasons respondents indicated they would be moderately to extremely likely to visit the website was to offer support or encouragement to other individuals with DM or to share personal experiences (Figure 2a). For individuals visiting the websites for personal reasons the most common reason was to seek support or encouragement from individuals with DM, to seek advice about clinical diabetes care, and obtain advice about life style changes (Figure 2b).

Behaviors associated with use of DM-specific social networking sites

Next, we separately examined self-reported behaviors reported by persons who completed the web-based survey data and those who completed the clinic based survey. Looking at the data from the web-based survey first, significant positive correlations were observed between respondents who offered advice on social media vs. their own self-reported eating (Figure 3a) and exercise habits (Figure 3b). Furthermore, using the website to obtain information on lifestyle changes for diabetes management was positively associated with following that advice (Figure 3c).

Clinic based surveys did reveal some significant differences between DM-specific social networking siteusers and non-users. Users had a slight but significant frequency in the number of days per week where they reported checking their glucose. DM-specific social networking siteusers reported checking their glucose on average 7 (1) days per week while non-users checked 6 (2) days per week ($P=.047$). Self-reported insulin therapy compliance was also slightly but significantly ($P=0.014$) higher among users of social media, with users taking insulin 7 (1) day per week and non-users 6 (2) days per week. No differences in other behaviors, such as dietary and exercise compliance, or compliance with oral medications, were detected.

Compliance, health care provider communication, and social media use

Survey data showed that 57/85 (69%) of respondents were moderately-extremely likely to follow the advice they received from the website about lifestyle changes for DM management, and 54/85 (65%) were moderately-extremely likely to follow the advice received from the website about clinical DM care (e.g., blood sugar monitoring, medications). Moreover, the information obtained from the websites helped about 52/85 (63%) of DM survey participants in communicating with their health care provider about their DM.

Discussion

Social media has now become an important source of health care information for patients and their caregivers. Patients use on-line resources to join the community of patients with similar diagnoses to engage, share information on management of their health conditions, and provide and receive support for themselves. Previous studies have shown that social media websites can help patients gain knowledge about DM and information to cope better with their daily management routine. However, little is known about the reasons they may visit these sites, or if visiting these sites somehow positively impacts diabetes self-management behaviors.

In the current study, we assessed DM-specific social networking site utilization to gain insight into how patients employ these resources, and to determine if there was any impact on self-management behaviors. Two different approaches were applied. First, an on-line survey was conducted of individuals while they were actively utilizing the website. This provided information on users only. Second, an assessment of a clinic based population of patients with DM was conducted. The second method, in addition to providing information on prevalence of DM-specific social networking site usage in a clinic based population, yielded preliminary data on the characteristics of users and non-users and differences in self-management behaviors between the groups.

Statistical comparisons are not appropriate between data derived from the websites and the clinic, but some similarities and differences in characteristics of survey participants can be noted in data derived from the two sources of information. For instance, the mean age of participants from the on-line survey and that of the clinic based survey was in the 50's. Additionally, website users in both surveys predominately used insulin, were predominately white, and had education beyond high school. Those who completed the survey on-line were comprised mostly of women and reported having balanced mixed of type 1 and type 2 DM. In contrast, DM-specific social networking site users who completed the clinic survey had a similar composition of men and women and were mostly patients with type 2 DM.

The clinic based survey indicated that the prevalence of DM-specific social networking site use, at least in this population, was low—only about a quarter of respondents stated they visited these sites. The clinic survey revealed some differences in users vs. non-users. Social media users were significantly younger, and a greater proportion had type 1 DM vs. non-users, where more had type 2 DM. Additionally, more users reported as not being married, and it could be speculated that a lack of family support drove more of the users to seek support on social media sites. Finally, a majority of users were employed, while non-users were either unemployed, students or retired. It is possible that work-life balance may have driven busier employed individuals to the convenience of social media use.

Beyond simply examining reasons for visiting DM-specific social networking sites, we also sought to evaluate whether utilizing these tools were associated with any specific desirable diabetes behaviors. For instance, when analyzing survey data completed on-line (i.e. in those actively using the websites), there was a positive correlation between the self-reported frequency of following a healthy dietary plan and performance of physical activity with going to the

website to offer advice about these activities. It is likely that individuals going to the sites to offer advice were already successful at self-management and wanted to pass on tips. Analysis of the clinic based surveys also revealed some positive impacts of DM social media use on reported self-management behaviors. Compared to non-users, users had a slight but significantly increased compliance with the frequency of weekly glucose monitoring and insulin administration.

Diabetes self-management education and providing individualized strategies to achieve metabolic and lifestyle goals, is integral to effective management. To this end, specific standards of care have been developed [15]. What has not been well studied is how contemporary social interactions, such as on-line social interactions that are common today, can be used to assist patients with diabetes to care more effectively for their condition. The data here suggests that such sites have the potential to be used to improve self-management behaviors.

There are limitations to the current study. First, the sample size of website users, both on-line and clinic based participants were small. In particular, the low participation in social media use noted in the clinic participants may have precluded detection of differences in other measures, such as HbA1c or body mass index. Furthermore, participants in both the web based and clinic survey overall had reasonably good glycemic control, as evidenced by the HbA1c (both self-reported from the on-line survey and measured from the clinic). In the clinic based survey, social media non-users had an HbA1c comparable to the users, so the non-users may have felt that additional advice (such as that gained from social media) may not have been needed to improve glycemic control. Finally, the survey was limited to English speakers only, respondents were largely of white race, and behaviors were self-reported.

Conclusion

Despite the limitations, results of this study provided insight into why individuals visit DM-specific social networking sites. Moreover, certain self-management behaviors, such self-monitoring of blood glucose and insulin administration may be improved. The results from the in-clinic surveys showed that only a small number of participants use social media for their diabetes management. Further work is needed to explore how to incorporate DM-specific social networking site use into the clinic environment and how to leverage the technology to assist patients with their condition.

Future work

The role of social media in management of DM remains relatively unexplored. Rather than a convenience sample (such as this study), a randomized control trial, appropriately statistically powered to detect differences in reported self-management behaviors or hemoglobin A1c, would be helpful. DM patients (who are currently non-social media users) could be randomized to visiting social media sites, with a control group maintaining usual care. Outcomes such as HbA1c and behaviors as measured here could be tracked. Future research that examines the relationship between online posting and diabetes-related self-care behaviors in a longitudinal design would help to clarify the role of website use in diabetes management. Lastly, including a more diverse race/ethnic patient population in future studies is needed.

Executive Summary

- Social media is becoming an important resource for health care information.
- There remains a paucity of data on how patients with diabetes mellitus (DM) use social media or how it may impact their behaviors.
- Both internet and clinic based surveys were conducted of patients with DM to assess the behaviors of individuals with DM who either offered or sought information on diabetes specific social media websites.
- Forty-five patients completed the web-based survey and 167 the clinic based survey, of whom only 40 visited social media sites.
- Respondents most often visited sites to offer support for DM or to seek such support for themselves.
- Analysis of on-line survey data indicated that self-reported adhering to lifestyle recommendations was significantly correlated ($P<0.01$) with visiting the sites.
- Clinic based survey data found that patients who reported using DM-specific web sites stated they monitored their home glucoses more often and reported better compliance with insulin administration (both $P<0.05$) compared to non-users.
- Study limitations included small sample size, lack of race/ethnic diversity of respondents, and self-reported behaviors.
- Further work is needed to explore how to incorporate DM social media use into the clinic environment and how leverage the technology to assist patients with their condition.

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Reference Annotations

In [12], the authors proposed a set of self-report measures helpful to study diabetes self-management behavior in DM patients. They reviewed data from 7 different studies, involving a total of 1988 DM patients. The questions related to diabetes-management are taken from the proposed study.

In [9], the authors performed a qualitative evaluation of communication among members in online diabetes specific Facebook groups. The analysis showed that the online platform acts as a forum for reporting personal experiences, asking questions, and receiving direct feedback for people living with diabetes. However, such online platforms are also targeted for promotional activities, with no accountability or checks for authenticity of the users in the forum. In our case, we collected the web surveys through moderated forums and in-clinic surveys are strictly moderated as the patients have come to the clinic for consultation.

In [8], the authors studied if social media and software tools improve diabetes control in patients with type 1 diabetes using insulin pumps with glucose sensors. This study showed that the patients gain diabetes knowledge and information and interact in their daily insulin adjustments. Our work is very similar in nature, instead of collecting the information from open Facebook groups, we conducted surveys on moderated diabetes specific forums and in-clinic settings.

Table 1: Demographic information of 45 participants participating on on-line survey.

Characteristic	Mean (SD) or N (%)
Age, y	57 (14)
Gender	
Women	30 (67%)
Men	15 (33%)
White race	45 (100%)
Diabetes Duration, y	17 (14)
Diabetes Diagnosis	
Type 1	21 (47%)
Type 2	22 (49%)
Other	2 (4%)
Prescribed insulin for diabetes	29 (64%)
Hemoglobin A1C, %	7.0% (2.2%)
Education	
Did not complete high school	1 (2%)
Completed high school	4 (9%)
Some college or vocational training	17 (38%)
Four year college or higher	23(51%)
Employment Status	
Working full or part time	12 (27%)
Unemployed/retired/student	33 (73%)

Table 2: Demographic information 167 diabetes patients completing clinic based questionnaire on use of social media.

Characteristic	Social media use		P-value
	Yes N=40	No N=127	
Age, y	54 (16)	64 (12)	<.01
Gender			0.36
Women	19 (48%)	50 (39%)	
Men	21 (52%)	77 (61%)	
White race	36 (90%)	112 (88%)	0.75
Diabetes Duration, y	13 (11)	16 (13)	0.23
Diabetes Diagnosis			0.034
Type 1	13 (33%)	18 (14%)	
Type 2	26 (65%)	104 (82%)	
Other	1 (2%)	5 (4%)	
Prescribed insulin for diabetes	35 (87%)	98 (77%)	0.16
Body mass index, (kg/m ²)	30.8 (5.5)	31.2 (6.7)	0.69
Hemoglobin A1C, %	7.7 (1.6)	7.6 (1.6)	0.66
Marital status			0.017
Married	18 (45%)	84 (66%)	
Not married	22 (55%)	43 (34%)	
Education			0.13
Did not complete high school	7 (17%)	17 (13%)	
Completed high school	2 (5%)	27 (21%)	
Some college or vocational training	14 (35%)	38 (30%)	
Four-year college or higher	17 (43%)	45 (35%)	
Employment Status			0.016
Working full or part	21 (52%)	40 (31%)	
Unemployed/retired/student	19 (48%)	87 (69%)	
Income, thousands of dollars			0.53

<55	13 (32%)	46 (36%)
55 to 99	11 (27%)	28 (22%)
100 to 150	7 (18%)	20 (16%)
>150	6 (15%)	12 (9%)
Declined to respond	3 (8%)	21 (17%)

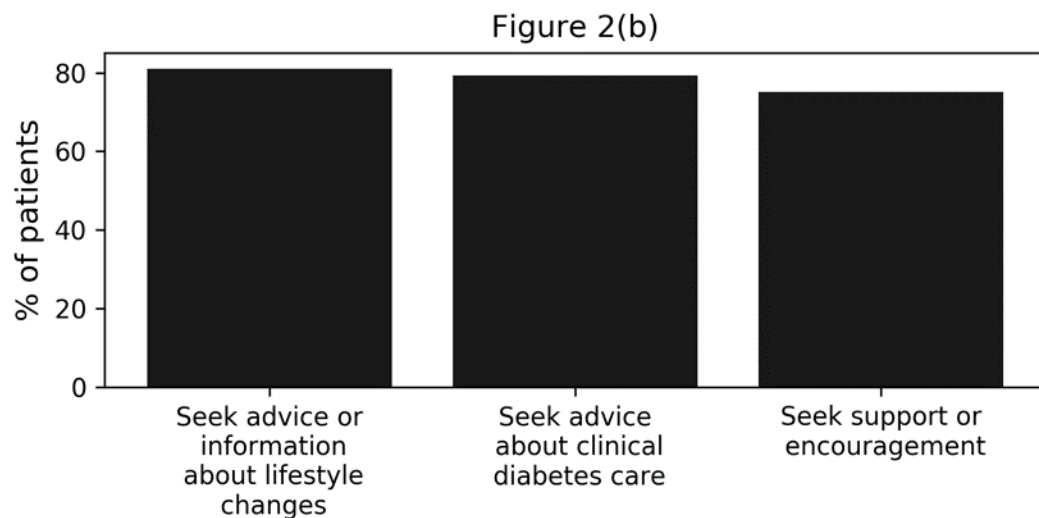
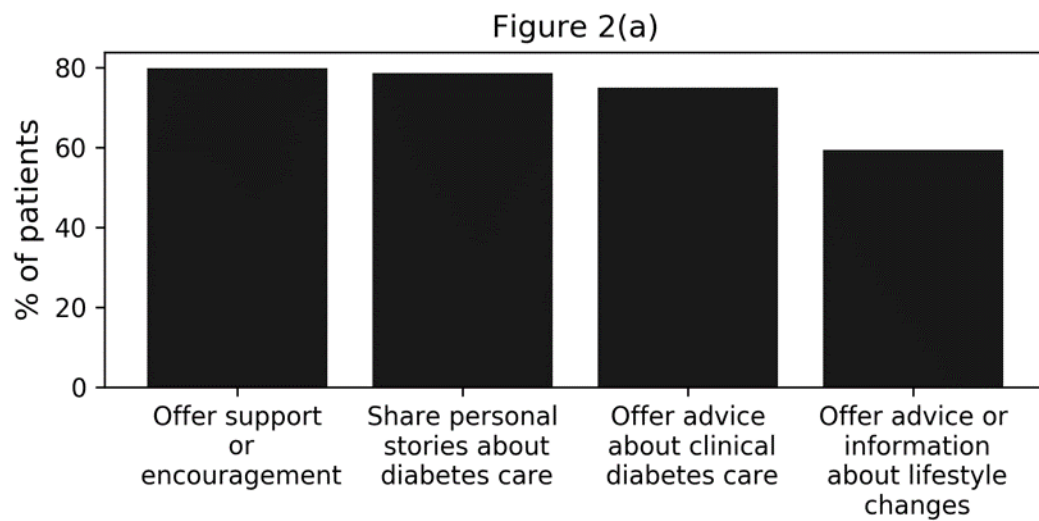


Figure 2: Top reasons DM survey participants who login to the social media websites at least 2-3 times a week to (a) post information and (b) seek advice.

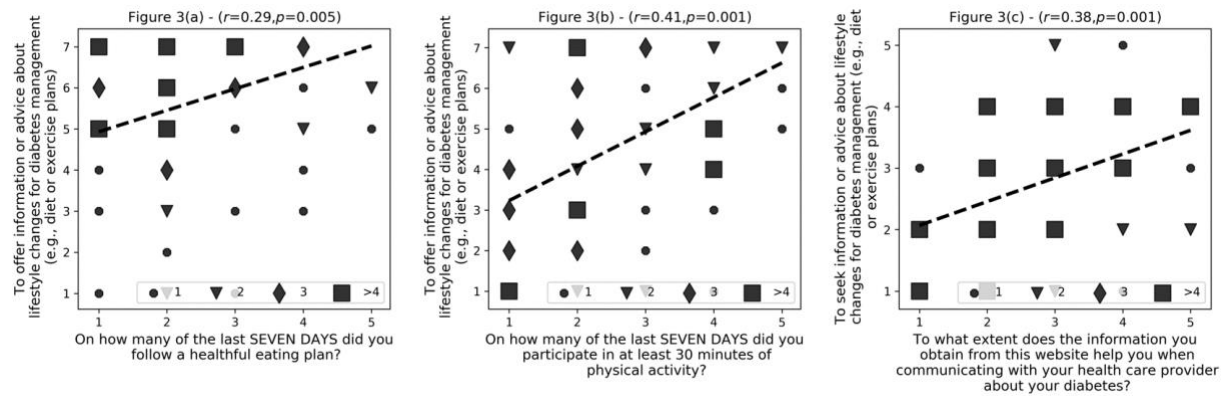


Figure 3: Correlation results between information or advice offering and seeking behavior and other behavioral traits of DM survey participants. The correlation parameters r and p -value are shown in the sub-figure title. The symbols represent number of respondents (circle=1 response, triangle=2, diamond=3, and square=4).

Figure legends

Figure 1: Diabetes survey questions.

Figure 2: Top reasons DM survey participants who login to the social media websites at least 2-3 times a week to (a) post information and (b) seek advice.

Figure 3: Correlation results between information or advice offering and seeking behavior and other behavioral traits of DM survey participants. The correlation parameters r and p -value are shown in the sub-figure title. The symbols represent number of respondents (circle=1 response, triangle=2, diamond=3, and square=4).