

Social Media Use among Individuals with Diabetes

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Abstract

Patients with chronic health conditions are often looking to the internet for information and support related to their illness. Little is known about the perceived helpfulness of online social networking and its relation to emotional outcomes and diabetes self-management. This paper describes a study surveying 244 participants of four national diabetes online communities in order to determine frequency, motivating factors, and preferences of social media use as well as related outcomes. Data demonstrated that participants are regularly active in diabetes online communities, with over half accessing such sites daily or even multiple times per day. Differences in frequency of use were not evidenced across age groups or relation to diabetes (i.e. patient versus loved one or caregiver). Almost half of the respondents indicated that they engage in diabetes social media use regularly regardless of health status or personal situation at the time. Topics of most interest when accessing diabetes-related social media included diabetes management, the latest technology, and nutrition. Implications for understanding the social support needs of individuals with diabetes and enhancing social media for this population are discussed.

Key Words: Diabetes, Social Media, Social Support, Caregivers

Background and Rationale

Patients with chronic health conditions are often looking to the internet for information and support related to their illness. The vast majority of US households have internet access, and over 83 percent of internet users have used the internet for health information (Pew Internet & American Life Project 2010). Social media, defined as “forms of electronic communication through which users create online communities to share information, ideas, personal messages, and other content” (Merriam-Webster 2012) can readily offer people health-related information and connections (Taylor, Wells, Howell, & Raphael 2012). An analysis of the ten most popular social media websites tailored to individuals living with a chronic disease found the sites to have an average of 6,700 members and up to 100 new posts daily, depending on the day and topics (Weitzman, Cole, Kaci, & Mandl 2011). While social media is a widely popular and frequently utilized outlet for patients with chronic disease, little research has demonstrated the perceived helpfulness and supportive aspects of social media and its relation to disease

management and health outcomes.

The current study focuses on social media use of patients with Type 1 diabetes and their caregivers, given that this disease requires a great deal of self-management and care and is associated with numerous mental health and social support needs (Peyrot et al 2005). Social support interventions have been linked to improved health and psychosocial outcomes for those with diabetes (Pouwer, Snock, vanderPloeg et al. 2001). Results from an in-person social support intervention highlighted that group consultations coupled with peer support via internet or phone were key elements to treatment gains (van Dam et al 2005). However, some aspects of social networking may not be as beneficial based on individual preferences (Sparud-Lundin, Orhn, & Danielson 2009; van Dam et al 2005). For instance, some young adults have reported that sharing experiences with others who have diabetes can be a “contradictory interchange” (Sparud-Lundin et al 2009) that feels forced because diabetes serves as the common denominator rather than other personal interests. Yet these same researchers found that others report feeling connected to those with diabetes because

it provides an "equal" to talk with and share experiences. Further research is needed to explore preferences for diabetes social support across age, gender, and other demographic groups, particularly in regard to online social support.

Two studies have examined the content of internet-based discussion groups for those with diabetes through thematic analysis of posts and group discussion threads. In one recent examination of Facebook networking by patients with diabetes, researchers found that sharing personal clinical information, requesting disease-specific guidance, and receiving emotional support were the most common topics among users (Greene et al., 2010). Similar topic areas were identified from a peer-to-peer discussion group used by a sample of patients with diabetes living in the United Kingdom (Armstrong, Koteyko, & Powell, 2011). Diabetes self-management, new possibilities in treatment, and coping psychologically with the disease were most commonly discussed among users. Thus, it seems that both information-seeking and emotional support are of importance for social media use among this population. These data may not represent the preferred topics of all participants belonging to these groups as direct participant report was not obtained. In addition, perceived helpfulness of participation in these groups would better inform how social media use may relate to patient outcomes.

Structured, internet-based intervention groups are another growing aspect of online social support use for those with diabetes and have demonstrated promising outcomes and favorability among participants. One examination of preferences for online diabetes support found that adults generally prefer professionally moderated discussion with content that includes both information and support (Zrebiec 2005). The effectiveness of a 12-week online intervention targeting physical activity was investigated among a sample of older patients with Type 2 diabetes – mean age = 54 years (Liebreich, Plotnikoff, Courneya, & Boule 2009). This program was hosted on a website containing didactic content and interactive components with elements of social networking such as message boards and personalized weekly emails from a counselor. Compared to those in a control group, intervention participants demonstrated increased amounts of physical activity and also reported high levels of satisfaction with the online delivery mode. Findings from an eight-week online support intervention for adolescents with Type 1 diabetes highlight knowledge gain, decreased isolation, and normalization of experience among the beneficial aspects reported by participants (Nicholas, Fellner, Frank, Small, Hetherington, Slater, et al. 2012).

A needs assessment of parents and service providers of adolescents with Type 1 diabetes was conducted by Canadian researchers in an effort to identify the most important elements for creating an online support intervention (Holtslander, Kornder, Letourneau, Turner, & Paterson 2012). Caregivers reported preferences for both informational and support-based content, which aligns with the content found in

many adult diabetes discussion groups (Armstrong et al., 2010; Greene et al. 2010). However, the specific informational and support needs of the parents and service providers differed from the adult respondents in other studies; they requested information related to and emotional support related to making transitions, and struggles with parenting and connecting with others. Further research should examine how patient preferences and actual use of social media may differ from caregivers or other family members (e.g., spouses). In addition, the perceived helpfulness of social networking and its relation to emotional outcomes and diabetes self-management has yet to be investigated.

Purpose of Current Study

The purpose of the current study was to address gaps in the current literature base regarding social media use among patients with diabetes and their parents or spouses. The specific objectives of the study were to garner the perspectives of this population in regard to the following areas of interest: 1) frequency of diabetes-related social media use, 2) common reasons for using social media related to living with diabetes, 3) common motivators for reading or sharing about diabetes in online communities, 4) relationship between diabetes-related social media use and happiness, health-related behaviors (e.g., diet and physical activity), and disease management (e.g., glucose monitoring), 5) specific ways, both positive and negative, in which people interface with social media, and 6) ideas to improve social media for people with diabetes. Such data can be used to inform further development and enhancement of diabetes-related social media content as well as assist professionals in better understanding the social support needs of those with diabetes in light of the expanding social media environment.

Method

A survey was administered to participants of four national diabetes social media communities, with access to international members as well. Participants had a diagnosis of Type 1 or were a parent or spouse of someone with diabetes. Respondents were 18 years or older and had access to a computer with internet capabilities. Non-English speakers were excluded because the survey was conducted in English only. Those without internet access were also excluded as the survey was administered online. A sample size of 244 was obtained in order to achieve adequate power for the descriptive data analyses at $\alpha = .05$.

To recruit participants, the research team posted and advertised the study with IRB-approved recruitment text containing a link to the survey at four widespread diabetes social media websites. These included: 1) Juvenile Diabetes Research Foundation (jdrf.org); 2) TuDiabetes (tudiabetes.org); 3) Children with Diabetes (childrenwithdiabetes.com); and 4) Diabetes Daily (diabetesdaily.com). Research examining the use of social media for diabetes has consisted largely of analysis of archival web-based content (Greene et al. 2010; Armstrong et al. 2011) and no pre-existing measures were available to address the specific

research objectives of the current study. Thus, a 14-question survey was developed by the research team and administered through a link to the survey on Survey Monkey, an on-line survey collection tool, at each of the participating social media websites.

A working definition of *social media* was provided at the beginning of the survey to enhance consistency of responses. Specifically, social media was defined as “diabetes-specific online communities to share information, ideas, and comments about diabetes”. Specific examples and non-examples were listed to better illustrate this definition. The survey was piloted among a small ($n = 6$) convenience sample to assess for any problems with completion as well as functionality of the online administration. No problems were reported from pilot participants; however, the format for two items was changed based on feedback regarding ease of response choices.

Participants first reviewed the informed consent text and, if they agreed to participate, completed the online survey. They also provided demographic information related to gender, age, and disease type and duration (either self or loved one). The estimated time commitment for each participant was 30 minutes or less.

Participant responses were anonymously recorded via the online Survey Monkey administration. Respondents could also elect to enter a gift card drawing as incentive for participation.

Descriptive statistics and correlation analyses were conducted to address the study objectives regarding diabetes-related social media use and relationship to other variables. Correlation coefficients were calculated between the quantitative variables of interest (gender, age, frequency of social media use, etc.), with an alpha level of .05 used to determine statistical significance.

Results

Demographic characteristics of the sample are displayed in Table 1. The majority of respondents (81%) were female; 60% were 18-30 years of age, 29% were 31-50 and 11% were over 50 years of age. The sample had a broad geographic representation both nationally and internationally, with participants across 27 states and eight countries. Most were individuals with Type 1 Diabetes (78%), followed by parents (18%), and spouses (4%)

Table 1 Demographic Characteristics of Participants

	n	%
<i>Gender</i>		
Male	46	19
Female	198	81
<i>Age</i>		
18-30 years	146	60
31-50 years	71	29
Over 50 years	27	11
<i>Participant Type</i>		
Person with T1D	190	78
Parent/Caregiver	44	18
Spouse	10	4
<i>Disease Duration</i>		
1-3 years	22	9
4-20 years	161	66
Over 20 years	61	25

(N = 244)

Duration of disease ranged from 1-50 years, with 66% of participants indicating a duration of 4-20 years, 9% with a 1-3 years duration and 25% with a duration of 20 years or more.

Participants varied in their frequency of diabetes-related social media use, and responses were quite evenly distributed across the response options provided. The highest percentage of respondents

indicated use at more than once per day (22%), followed by 4-6 times per week (16%), and 2-3 times per week (15%). Thirteen percent used social media only 1-2 times during the past month. Frequency of use was not significantly related to gender ($r = .02, p > .05$), age ($r = -.02, p > .05$) nor to the respondent's connection to diabetes ($r = .03, p > .05$). All correlations are displayed in Table 2.

Table 2 Correlations between demographic variables, social media use, and perceived outcomes

	Gender	Age	Connection to Diabetes	Frequency of Use	Mood	Motivation	Confidence
Gender	1.00						
Age	.07	1.00					
Connection to Diabetes	-.07	.53*	1.00				
Frequency of Use	.02	-.02	.03	1.00			
Mood	-.03	-.08	.01	.22*	1.00		
Motivation	.04	-.10	.12	.22*	.31*	1.00	
Confidence	-.01	-.08	.06	.16*	.43*	.67*	1.00

* $p < .05$

The three most frequently cited reasons for using diabetes-related social media included: 1) finding information related to diabetes care and management, 2) networking and finding others with common experiences and 3) finding information related to coping with diabetes. Having one's voice heard (i.e. blogging) was endorsed as the least important reason for use. Participants were also asked to indicate situations that motivate them to read or share about diabetes in online communities. Forty percent reported that they access social media related to diabetes very regularly, regardless of health status or personal situation at the time. For those that did feel motivated by specific events, seeking specific information to problem-solve a diabetes issue was most commonly endorsed (23%), followed by experiencing diabetes burn-out (12%). Respondents shared other motivating factors to include wanting information about the latest technology or research and needing help to cope. Overall, diabetes management was the most preferred topic to read about among online users. Technology and nutrition were also endorsed as beneficial topic areas. Information about relationships was the least preferred.

In regard to the relationship between diabetes-related social media use and overall functioning, 72% reported experiencing an improvement in their mood immediately after reading or sharing about diabetes online. The frequency with which individuals used social media had a significant, positive relationship with mood ($r = .22, p < .001$). Similar relationships were also evidenced between frequency of use and increased motivation to be healthy or support a loved one's health ($r = .22, p < .01$) as well as increased confidence in one's own diabetes management ($r = .16, p < .05$). Thus, those who more frequently participated in diabetes-related online communities reported greater boosts in mood, motivation, and confidence than less frequent users.

Participants were also asked to select the most significant way in which social media has benefitted them or their loved one. Feeling connected was identified as the greatest benefit (41% of respondents), along with gaining more knowledge (40%). Less endorsed benefits included making friends (9%), finding humor (7%), and improved blood sugar control (3%).

To further illustrate the ways in which members of diabetes online communities interface with the sites and fellow users, two open-ended prompts were provided. First, participants were asked to share how they handle receiving negative feedback from others online. The most common strategy for handling negative or unexpected comments was to ignore them. This approach was utilized by 33% of the participants who responded. Statements such as "*I would block it or ignore it*" and "*Ignore and move forward*" demonstrate this theme. The next most commonly endorsed strategies, ordered by frequency, included a) just 'rolling with it' or trying to not take it personally, b) focusing on positive feedback instead of negative feedback, c) discussing the feedback further with the person leaving the comment or with a friend or family member, or d) leaving the site. One example of discussing the feedback further was "*I would question their reasoning and ask for further explanation as to why they responded in such a way.*" Other strategies noted by only a few participants were laughing it off, getting angry or upset, or feeling unsure of how to respond. For instance, in regard to feeling unsure, one person wrote "*I don't know. Maybe that is why I post so little.*"

Another way in which respondents highlighted their interactions online was by describing their most memorable social media experiences. Responses varied greatly across individual participants, highlighting the diversity of personal experiences with diabetes social media. Participants shared specific events or memories as well as more global benefits to being a part of diabetes communities. Specific events included things such as helping another user (e.g., "*helping someone who was newly diagnosed feel a bit calmer*") and receiving positive feedback after a personal accomplishment (e.g., "*reading the responses after I completed my first half marathon with T1D*"). In terms of broader memorable experiences, gaining appreciation for a support network was the most frequently reported theme, reflected by sentiments such as these:

[This online community] has given me a second family...a diabetes family" and "On the [message] boards you are not bothering anyone by asking –

they answer because they want to, not because they were asked.

Other themes for broader memorable experiences included feeling motivated by others to improve health habits, staying abreast of diabetes-related technology, and feeling understood or connected with others with similar experiences.

Finally, participants shared their recommendations to inform future social media content for the diabetes community. Recommendations varied a great deal but the most commonly occurring themes were: a) interdisciplinary input/advice on various aspects of diabetes care, b) latest technology and research explained in simple terms, c) use of humor or more lighthearted content, d) forums for different age groups to interact, and e) ways to make local community connections. Statements reflecting the need for interdisciplinary input included *"a separate forum with doctors, diabetic educators, and nurses on call constantly"* and *"definitely a section about mental health and coping"*.

The theme of latest technology was emphasized in statements such as *"up-to-date technology and advancement."* Comments related to more use of humor included *"More lighthearted content; sometimes it's just so depressing"* and *"a spot for humorous stories."* In regard to forums for different age groups, participants shared things such as *"maybe put discussion boards by age"* and *"a place for kids to connect based on age"*.

Lastly, statements reflecting the desire for local community connections included *"finding people close to my hometown that I could meet up with."* and *"national and local discussion boards for when you want to be able to connect with those who live near you"*. Other suggestions noted by only a few participants included information on how to educate others about diabetes, links to scholarships and career opportunities, and a guide for those who are recently diagnosed.

Limitations

Results of the current study should be considered in the context of certain methodological limitations. First, while the sample utilized in the current study was nationally and even internationally diverse, participants were not equally represented in regard to other demographic characteristics, including gender and age. Thus, generalizability to the larger population is limited and future research should explore the characteristics of social media use among those underrepresented in this study, particularly males and older individuals, to determine whether findings are similar. In addition, the convenience sample used to pilot the survey was quite small, limiting the amount of feedback regarding survey functionality and needed changes. Second, utilizing four separate diabetes social networking sites somewhat confounded the working definition and past experiences with social media, as these sites differ in terms of content and users. Analyses were not separated according to sites from which they were pulled so results should be considered

in the context of these inherent differences. Lastly, as with all surveyed responses, there is a possibility of socially desirable responding, although the research team attempted to address this to some degree by collecting all data anonymously.

Conclusions and Implications for Practice

This study highlights the social media habits, opinions, and experiences from a geographically diverse sample of diabetes online community participants. This information adds to the current literature gap on the perceived benefits and purpose of health-related social media use. More importantly, these data can be used to enhance this type of social support for individuals with diabetes.

Overall, participants are regularly active in diabetes online communities, with over half accessing such sites daily or even multiple times per day. Notably, differences in frequency of use were not evidenced across gender, age groups, or one's connection to diabetes (i.e. patient, spouse, or parent). The findings pertaining to age differ from previous research in which social media use for healthcare information declined among older patients (Fisher & Clayton 2012). However, only 11% of the current sample was over 50 years of age, and unequal representation across groups limits the ability to draw direct comparisons. While findings from the current study do not reflect a decrease in use with age, respondents did express a desire for age-specific online forums. Thus, social media sites may be enhanced by providing separate forums designed with developmentally appropriate language and information across age groups or other demographic characteristics such as one's connection to diabetes (i.e. patient, spouse, caregiver).

Individuals participate in diabetes social media for a variety of reasons, but close to half of the respondents indicated that they engage regularly regardless of health status or personal situation at the time. This illustrates the need for social media content to be broad-reaching, considering that many users are not participating due to specific health or personal circumstances. Gaining more education was one of the greatest benefits of social media perceived by participants, and preferred topics to read about online included diabetes management, technological advancements, and nutrition. The social connection and support aspect of diabetes-related social media was also a key benefit to online users. However, while people were looking for this connection, topics related to relationships or social-emotional functioning were not of the same interest level as topics related to physical functioning and diabetes care. This suggests that increasing the amount of site content that is educational in nature and relates to physical health and self-management may be an appealing enhancement to social media sites for many individuals.

Social media use among those with diabetes is a personal experience that comes with a diverse array of preferences and motivating factors. The current study demonstrates the positive impact that online social support provides for the majority of individuals, including

improved mood, confidence, and diabetes management. These relationships underscore the importance of keenly attending to the opinions and preferences of social media users to further enhance their health and social-

emotional functioning. Future studies may examine these links more closely by relating the use of diabetes-related social media with objective health indicators.

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