Original Paper

Effect of Diabetes Online Community Engagement on Health Indicators: Cross-Sectional Study

Michelle L Litchman[1,2*], PhD, FNP-BC, FAANP; Linda S Edelman[1*], RN, PhD; Gary W Donaldson[1,3*], PhD

[1] College of Nursing, University of Utah, Salt Lake City, UT, United States
[2] Utah Diabetes and Endocrinology Center, Salt Lake City, UT, United States
[3] Department of Anesthesiology, University of Utah, Salt Lake City, UT, United States
[*] all authors contributed equally

Corresponding Author:
Michelle L Litchman, PhD, FNP-BC, FAANP
College of Nursing
University of Utah
10 South 2000 East
Salt Lake City, UT, 84112
United States
Phone: 1 801 585 9612
Email: michelle.litchman@nurs.utah.edu

Abstract

Background: Successful diabetes management requires ongoing lifelong self-care and can require that individuals with diabetes become experts in translating care recommendations into real-life day-to-day diabetes self-care strategies. The diabetes online community comprises multiple websites that include social media sites, blogs, and discussion groups for people with diabetes to chat and exchange information. Online communities can provide disease-specific practical advice and emotional support, allow users to share experiences, and encourage self-advocacy and patient empowerment. However, there has been little research about whether diabetes online community use is associated with better diabetes self-care or quality of life.

Objective: The aim of this study was to survey adults with diabetes who participated in the diabetes online community to better understand and describe who is using the diabetes online community, how they are using it, and whether the use of the diabetes online community was associated with health indicators.

Methods: We recruited adults diagnosed with diabetes who used at least one of 4 different diabetes-related online communities to complete an online survey. Participants' demographics, reported glycated hemoglobin (HbA_{1c}), health-related quality of life (SF-12v2), level of diabetes self-care (Self-Care Inventory-Revised), and diabetes online community use (level of intensity and engagement) were collected. We examined the relationships between demographics, diabetes online community use, and health indicators (health-related quality of life, self-care, and HbA_{1c} levels). We used binary logistic regression to determine the extent to which diabetes online community use predicted an HbA_{1c} <7% or ≥7% after controlling statistically for other variables in the model.

Results: A total of 183 adults participated in this study. Participants were mostly female (71.6%, 131/183), white (95.1%, 174/183), US citizens (82.5%, 151/183), had type 1 diabetes (69.7%, 129/183), with a mean age of 44.7 years (SD 14) and diabetes duration of 18.2 years (SD 14.6). Participants had higher diabetes self-care (*P*<.001, mean 72.4, SD 12.1) and better health-related quality of life (physical component summary *P*<.001, mean 64.8, SD 19; mental component summary *P*<.001, mean 66.6, SD 21.6) when compared with norms for diabetes. Diabetes online community engagement was a strong predictor of A_{1c}, reducing the odds of having an A_{1c} ≥7% by 33.8% for every point increase in diabetes online community engagement (0-5). Our data also indicated that study participants are oftentimes (67.2%, 123/183) not informing their healthcare providers about their diabetes online community use even though most (91.2%, 161/181) are seeing their healthcare provider on a regular basis.

Conclusions: Our results suggest that individuals highly engaged with diabetes online community are more likely to have better glycemic levels compared with those with lower engagement. Furthermore, diabetes online community users have high health-related quality of life and diabetes self-care levels. Supplementing usual healthcare activities with diabetes online community use may encourage knowledge and support among a population that needs to optimize its diabetes self-care. Further studies are needed to determine how diabetes online community engagement may affect health outcomes.

(JMIR Diabetes 2018;3(2):e8) doi: 10.2196/diabetes.8603

KEYWORDS

diabetes; online peer support; social media; eHealth; quality of life; self-care; A1c

Introduction

Background

The internet is increasingly used as a source of health information. In fact, 79% of adults in the United States use the internet and, of those, 59% are looking for health information [1]. It is observed that 23% of individuals with chronic conditions look online to find someone with similar health concerns [2]. Websites that allow interaction and crowdsourcing the collective wisdom of others [3] can help patients manage their own health by providing tools for health promotion and disease self-care, decision support, support for behavior change, and access to online communities [4]. Online communities can support health literacy by crowdsourcing information to support medical decision making [5,6]. Although many patients are using online information and communities to improve health [7] and engagement, how online activity affects health outcomes is poorly understood, and measuring meaningful eHealth engagement can be difficult [8].

As diabetes is a complex condition, some people with diabetes find patient peers helpful in providing support for managing their disease. Engagement in peer health is defined as the interaction, education, and support offered by peers with the same condition to promote self-care. Peers who receive special training can provide assistance in day-to-day chronic disease management, encourage appropriate clinical care, and offer ongoing social and emotional support [9,10]. Trained peers with diabetes have provided formal face-to-face support or discussion groups [10,11], phone calls [10,12,13], text support, and home visits [10]. Diabetes-related peer health has been associated with increased knowledge [14,15], self-efficacy [11,12,16], patient activation [11,16], communication with physicians, healthier eating habits [11,17], and improved hemoglobin A_{1c} [13,15-24]. Importantly, reciprocal peer support has been found to be better than nurse care management with regard to glycated hemoglobin (HbA_{1c}) reduction [13]. The American Diabetes Association and American Association of Diabetes Educators recognize peers as an important factor in diabetes self-care [25,26]. However, the informal or unstructured peer support provided by the diabetes online community (DOC) has not been fully addressed.

Diabetes Online Community

The DOC is a grassroots online community developed for the purpose of sharing knowledge and support based on the user's experience of living with diabetes. Individuals involved in the DOC were initially those living with diabetes themselves, although the community has expanded and now includes family, friends, healthcare providers, and industry representatives [27]. DOC provides a vehicle for individuals to learn practical diabetes self-care techniques from experienced peers with shared experiences [27-29], and can be a source of confidence in diabetes self-care [30], inspiration, motivation, and encouragement [31], all of which support health literacy. The DOC includes blogs, video vlogs, discussion boards, and diabetes-specific (ie, Reality Check, TuDiabetes, Diabetic Connect, Beyond Type 1, Diabetes Daily) and general social media sites (ie, Facebook, Twitter, Instagram).

The DOC can be accessed through stand-alone interactive websites or social media sites. DOC users can actively contribute to discussions or passively view posts without contributing to the discussion [32]. DOC users engage in peer health [33,34] to gain practical advice [35-38], emotional support [35-41], shared experience [37-39], and improved coping [42] and empowerment [40]. There is limited data on negative patient outcomes related to DOC use [43]; however, misinformation on social media sites is infrequent [35,36,44,45] and quickly corrected by other members in the discussion group [35,39].

Currently, we are not aware of any research examining the relationship between DOC engagement and health behaviors.

Objective

The overarching purpose of this study was to better understand DOC users and how DOC engagement is related to self-reported health outcomes. The specific aims of this exploratory and descriptive study were threefold: (1) to describe DOC users in terms of demographics, diabetes type, and diabetes-related treatment; (2) to describe intensity of use and levels of engagement of DOC users; and (3) to examine the relationship between DOC use (intensity and engagement) and health-related quality-of-life, self-care behaviors, and HbA_{1c} levels.

Methods

Study Design

We conducted an exploratory cross-sectional study of a convenience sample of DOC users using an online survey posted to 4 distinct DOC social media sites. First, we conducted a small pilot study of DOC users (n=5) and asked for input from 2 diabetes specialty healthcare providers to guide survey development, and to address usability and technical functionality. The final 129-item survey included questions about demographic information, health history, eHealth app use, DOC intensity and engagement, health-related quality of life (HRQoL) [46], and diabetes self-care behaviors [47]. We used Research Electronic Data Capture (REDCap) Survey software (Nashville, TN) to administer the survey. REDCap survey is a secure, Web-based study management system.

Sample

Adult DOC users (18 years and older) with a diagnosis of type 1 or type 2 diabetes, or Latent Autoimmune Diabetes of Adulthood (LADA) who could read English, were eligible for the study. Any participant who identified themselves as having gestational diabetes, being a caregiver for someone with diabetes (ie, parent of a child with diabetes), or younger than 18 years were excluded from the analyses. The study was approved by the University of Utah Institutional Review Board, Salt Lake City, UT. The study was also approved by the administration team from TuDiabetes and Diabetic Connect; the other 2 sites were Facebook and Twitter.

Recruitment and Setting

We recruited adult DOC users in 2 waves. We selected the initial site, TuDiabetes, because it was hosted by a nonprofit organization, the Diabetes Hands Foundation, that did not allow advertisements. TuDiabetes members were screened by an administrator before they could join, posts could be viewed by members without logging in to their account. TuDiabetes had more than 35,000 members with diabetes at the time of the study. Initially, we posted a synopsis of the study with a link to the survey on the principal investigator's TuDiabetes profile page, which was shared by key opinion leaders and mentioned in the TuDiabetes online newsletter. The first question of the survey asked individuals if they consented to participate in the study and provided a link to further information about the study purpose and method.

A second wave of recruitment included Diabetic Connect, a for-profit organization, which was selected because of its growing diabetes-specific social media presence. Facebook and Twitter were also used for recruitment, given the number of groups, pages, and tweet chats focused on diabetes. Data collection occurred over a 7-month period.

Measures

The online survey was divided into 6 sections: (1) demographics, (2) health history, (3) eHealth use (including reasons to join a diabetes social network, DOC intensity, DOC engagement, and internet social capital), (4) HRQoL, (5) diabetes self-care behaviors, and (6) source credibility. Moreover, 5 validated instruments were used and included the SF-12v2 [46,48], an adapted version of the Facebook intensity scale [49], an adapted version of the internet social capital scale [50], Self-Care Inventory-Revised (SCI-R) [47], and the source credibility scale [51]. This paper will examine demographics, health history, eHealth use as noted below (that includes reasons to join a DOC, DOC intensity, and DOC engagement, but does not include internet social capital), HRQoL, and diabetes self-care behaviors. Details for each measure are noted below.

Demographics

A total of 11 demographic items focused on gender, marital status, education level, employment, annual household income, age, ethnicity, race, country or state, living setting, and insurance status.

Health History

A total of 8 self-reported items focused on diabetes type, diabetes duration, current diabetes treatments, most recent HbA_{1c} level, type of medical practice, and type of healthcare provider used for diabetes care, frequency of diabetes provider visits, and presence of diabetes-related complications.

eHealth Use

A total of 22 items, individually scored, were asked to measure how participants navigate the DOC and if the participants' healthcare provider knew about and supported their DOC use.

Reasons to Join the Diabetes Online Community

A total of 13 items were developed based on an anecdotal dLife (Diabetes Life) report [52] that addressed the reasons why someone with diabetes should join the DOC. Items were dichotomous, allowing a yes or no response.

Diabetes Online Community Intensity

The DOC intensity scale is an 8-item tool adapted from the Facebook intensity scale [49] to measure how often and for how long individuals are engaged in the DOC, and to determine the emotional connectedness and integration into daily activities. Scores range from 0 to 5, with higher scores indicating more DOC intensity. Cronbach coefficient for DOC intensity was .85.

Diabetes Online Community Engagement

The DOC engagement scale is a 5-item tool developed by the authors and informed by a qualitative analysis [36] to measure engagement or interaction with other DOC users. Specifically, this tool was used to measure whether or not participants shared clinical information, requested or provided clinical guidance or feedback, or received or provided emotional support. Scores range from 0 to 5, with higher scores indicating more DOC engagement. Cronbach coefficient for DOC engagement was .73.

Health-Related Quality of Life

SF12-v2 is a 12-item tool used to measure physical and mental health status. A 4-week recall was used in this study. Norm based scoring (mean 50, SD 10) was used for this analysis [46]. Cronbach coefficient for SF-12v2 was .88 (physical=.77 and mental=.86).

Diabetes Self-Care

SCI-R is a 15-item tool used to measure diabetes self-care behaviors and can accommodate natural variation in treatment plans for patients with type 1 and type 2 diabetes. Scores range from 0 to 100 [47]. Cronbach coefficient for the SCI-R was .68.

Analysis

In a survey study such as ours, precision of parameter estimation is the key sample size criterion. We defined excellent precision operationally as an 80% probability of obtaining 95% confidence intervals for the mean, with half-width no greater than 0.15 SD. This criterion provides interval estimation with symmetric uncertainty that is smaller than Cohen familiar standard for a "small" effect. Under the 2-sided *t*-distribution, a sample size of 189 was required to meet this criterion, which conservatively guided our recruitment of a sample of 207. The final sample of 183 participants successfully achieved an 80.5% probability of 95% CI precision limited to 0.151 SD units.

Survey responses were identified by a participant number code, and all the study-related files were maintained in REDCap. Data were screened for multiple entries. In accordance with standard scoring methods, missing data were imputed with appropriately scaled item means in the calculation of total scores for the validated scales. All other missing data were excluded pairwise. Missing data made up less than 10% of each analysis. We performed statistical analysis using SPSS 21 (IBM) [53] and used exploratory data analysis to screen for errors, determine frequencies, and identify normality of distribution patterns. Cronbach alpha was calculated for each validated measure.

The primary goal was to gather detailed data on DOC users, both demographically and in terms of intensity and engagement in using the DOC, and to describe any relationship between DOC use and health indicators (HRQoL, self-care, and HbA_{1c} levels). To address our first aim, we ran frequencies for each demographic variable and used analysis of variance and Chi-square tests to examine if there were differences in demographic variables based on diabetes type. To address our second aim, scores for DOC intensity and DOC engagement were averaged. Analyses were conducted to determine relationships between, and interactions among, demographic variables, health history, eHealth use, DOC intensity, DOC engagement, HRQoL, and diabetes self-care behaviors, to address our third aim. This included correlations between DOC intensity, DOC engagement, HRQoL, and diabetes-self-care, as well as between the support participants received from their healthcare providers related to their DOC use, DOC intensity, and DOC engagement scores. A one sample *t* test was used to compare the studied sample with norms for diabetes related to health status [46] and diabetes self-care [47].

Variables that predicted the dichotomous outcome of HbA_{1c} <7% or ≥7%, based on the American Diabetes Association’s recommendations for an HbA_{1c} <7% [54], were examined in a simultaneous model among DOC users. To explore this, variables were analyzed based on researcher and DOC key opinion leader knowledge of the DOC in an initial stepwise logistic regression. Stepwise logistic regression allowed us to refine the variables and to remove nonsignificant variables. We then used a simultaneous logistic regression in the final predictive model. For inference, alpha was set at .05.

Results

Recruitment

There were 1501 unique DOC site visitors who viewed the online recruitment post and 207 unique participants who completed the survey. Of those, 183 met the inclusion criteria, giving us a recruitment rate of 12.2%. Table 1 shows participant demographic data. Participants were more likely to be female, white, living in the United States in a suburban setting, well educated, employed, and to have type 1 diabetes. Participants with type 1 diabetes were younger than those with type 2 diabetes (*P*<.001), or those with LADA (*P*=.002).

Health History

Most of the participants reported receiving care for their diabetes at an endocrinology office (68.1%, 124/182), although those with type 2 diabetes were more likely to be seen by a family practice provider than those with type 1 diabetes (*P*<.001). Participants saw their healthcare providers at least quarterly (63.5%, 115/181) or every 6 months (23.8%, 43/181).

Participants had an average of 1.2 diabetes-related complications; there was a positive correlation between number of diabetes-related complications and diabetes duration (*r*=.369, *P*<.001). Those with type 1 diabetes were more likely to report depression (*P*=.01), heart disease (*P*=.01), and eye disease (*P*<.001) than those with type 2 diabetes or LADA. Over half (59.0%, 108/183) of individuals reported diabetes-related complications. Most commonly reported diabetes-related complications included depression (32%, 59/183), cardiovascular disease (27%, 49/183), retinopathy (21%, 38/183), and neuropathy (19%, 35/182). Diabetes treatments varied, although majority of the participants were using intensive insulin management (85%, 155/183). Of those undergoing intensive insulin management, 54.8% (81/147) were using an insulin pump, whereas 25.2% (37/147) were using a continuous glucose monitor. Respondents with type 1 diabetes had a longer diabetes duration than those with type 2 diabetes or LADA (*P*<.001).

eHealth Use

Participants used an average of 2.6 devices to access the internet. The majority (96.2%, 175/183) of participants spent their time reading (91.3%, 167/183), responding (74.3%, 136/183), and creating original posts (59.6%, 109/183). The time for which participants had been using DOC ranged from less than 1 year (32%, 58/183) to 1 to 3 years (37.7%, 69/183), or more than 3 years (30.4%, 56/183). The majority of respondents had not told their healthcare providers about their DOC use (67.2%, 123/183). Of those who did tell their healthcare providers about their DOC use, 60% (36/60) were supported to continue doing so, 1.9% (3/183) were not supported, and 10.9% (20/183) were not sure if their provider supported their use of the DOC.

Reasons to Join a Diabetes Online Community

A majority of the participants found participating in the DOC beneficial as it related to knowledge attainment, support, and empowerment; see Table 2. DOC users who found a benefit in their participation with the DOC reported higher DOC intensity and DOC engagement; see Table 3.

Table 1. . Demographics by type of diabetes.

Characteristics	Type 1 diabetes (n=129)	Type 2 diabetes (n=33)	LADA[a] (n=21)	Total	*P* value
Age in years, mean (SD)[b]	41 (13.6)	51.2 (11.4)	52.6 (13.7)	44.7 (14.0)	<.001
Diagnosis (duration in years), mean (SD)[b]	22.5 (14.6)	6.4 (5.7)	10.4 (10.2)	18.2 (14.6)	<.001
Gender, n (%)[c]					.09
Male	31 (24.4)	14 (42.4)	4 (20)	49 (26.8)	
Female	96 (75.6)	19 (57.6)	16 (80)	131 (71.6)	
Ethnicity, n (%)[c]					.27
Hispanic or Latino	6 (4.7)	0 (0.0)	0 (0)	6 (3.3)	
Not Hispanic or Latino	121 (95.3)	33 (100)	21 (100)	175 (95.6)	
Race, n (%)[c]					.73
American Indian or Alaskan Native	2 (1.6)	0 (0.0)	0 (0)	2 (1.1)	
Asian	2 (1.6)	0 (0.0)	1 (5)	3 (1.6)	
African American	2 (1.6)	0 (0.0)	0 (0)	2 (1.1)	
White	122 (95.3)	33 (100.0)	19 (95)	174 (95.1)	
Country, n (%)[c]					.64
United States	108 (84.4)	27 (81.8)	16 (76.2)	151 (82.5)	
Not United States	20 (15.6)	6 (18.2)	5 (24)	31 (16.9)	
Living setting, n (%)[c]					.03
Rural	16 (12.4)	11 (33.3)	6 (28.6)	33 (18.0)	
Suburban	78 (60.5)	16 (48.5)	8 (38.1)	102 (55.7)	
Urban	35 (27.1)	6 (18.2)	7 (33.3)	48 (26.2)	
Income, n (%)[c]					.58
Less than US $30,000	28 (23)	12 (36.4)	3 (16.7)	43 (23.5)	
US $30,000-$49,999	20 (16.4)	5 (15.2)	5 (27.8)	30 (16.4)	
US $50,000-$74,999	24 (19.7)	6 (18.2)	4 (22.2)	34 (18.6)	
Education, n (%)[c]					.001
Some high school	2 (1.6)	0 (0.0)	0 (0)	2 (1.1)	
High school graduate	5 (3.9)	6 (18.2)	0 (0)	11 (6.0)	
Some college	13 (10.2)	7 (21.2)	8 (38.1)	28 (15.3)	
Associate’s degree	11 (8.6)	6 (18.2)	3 (14.3)	20 (10.9)	
Bachelor’s degree	54 (42.2)	8 (24.2)	4 (19)	66 (36.1)	
Graduate degree	43 (33.6)	6 (18.2)	6 (28.6)	55 (30.1)	
Employment, n (%)[c]					.19
Student	12 (9.3)	2 (6.1)	1 (5)	15 (8.2)	
Unemployed	8 (6.2)	5 (15.2)	1 (5)	14 (7.7)	
Working part-time	20 (15.5)	4 (12.1)	3 (15)	27 (14.8)	
Working full-time	67 (51.9)	13 (39.4)	10 (50)	90 (49.2)	
Retired	9 (7)	6 (18.2)	5 (25)	20 (10.9)	
Disabled	13 (10.1)	3 (9.1)	0 (0)	16 (8.7)	
Insurance, n (%)[c]					.63
Insured	111(92.5)	32(97)	19 (95)	162 (88.5)	

Characteristics	Type 1 diabetes (n=129)	Type 2 diabetes (n=33)	LADA[a] (n=21)	Total	*P* value
Uninsured	9 (7.5)	1 (3)	1 (5)	11 (6.0)	
Treatment, n (%)[c]					<.001
No medications	0 (0)	3 (10)	0 (0)	3 (1.6)	
Oral agents only	0 (0)	15 (45)	0 (0)	15 (8.2)	
One injection[d]	0 (0)	7 (21)	3 (14)	10 (5.5)	
Intensive insulin	129 (100)	8 (24)	18 (86)	155 (84.7)	
Type of practice, n (%)[c]					<.001
Endocrinology	101 (78)	8 (24)	15 (75)	134 (67)	
Internal medicine	14 (11)	8 (24)	0 (0)	22 (11.9)	
Family practice	12 (7)	15 (46)	3 (15)	30 (16.2)	
Community clinic	2 (2)	1 (3)	1 (5)	4 (2.2)	
Other	0 (0)	1 (3)	1 (5)	2 (1.1)	

[a] Latent autoimmune diabetes of adulthood.

[b] Analysis of variance.

[c] Chi-square.

[d] One injected medication (ie, basal insulin, incretin mimetic) with or without oral medications.

Table 2. . Reasons to join a diabetes online community (DOC); N ranges from 169 to 176.

Reason to join a DOC	n (% stating yes)
The DOC helped me learn research and treatment alternatives	146 (83.4)
The DOC allows me to help others	142 (80.9)
The DOC helped me learn new diabetes management strategies	139 (80.3)
The DOC helps me feel understood	138 (79.3)
The DOC helped me get answers to many of my diabetes questions	133 (76.0)
The DOC helps me feel less alone	128 (75.7)
The DOC helps me feel more empowered	128 (73.1)
The DOC allows me to make new friends	113 (66.1)
The DOC helped me learn about potential side effects of drugs or devices	112 (64.0)
The DOC helped me learn things that my healthcare provider did not know	102 (60.0)
The DOC helps me feel support through rough times	99 (57.9)
The DOC helped me learn strategies to improve insurance coverage for diabetes-related medications or supplies	84 (47.7)
I discussed a topic I learned about on the DOC with my healthcare provider	82 (48.5)

Table 3. Relationship between diabetes online community (DOC) benefits, intensity, and engagement; N ranges from 169 to 176.

DOC benefit	DOC intensity		DOC engagement	
	Mean (SD)	*P* value	Mean (SD)	*P* value
Feel understood		<.001		<.001
Yes	3.0 (0.65)		2.7 (1.6)	
No	2.1 (0.64)		1.2 (1.3)	
Feel less alone		<.001		<.001
Yes	3.0 (0.62)		2.7 (1.7)	
No	2.2 (0.60)		1.4 (1.2)	
Feel more empowered		<.001		<.001
Yes	3.0 (0.63)		2.8 (1.6)	
No	2.1 (0.60)		1.0 (1.1)	
Feel support through rough times		<.001		<.001
Yes	3.1 (0.62)		2.92 (1.6)	
No	2.4 (0.70)		1.57 (1.5)	
Learn new diabetes management strategies		<.001		<.001
Yes	2.9 (0.67)		2.6 (1.6)	
No	2.1 (0.64)		1.4 (1.4)	
Learn research and treatment alternatives		<.001		<.001
Yes	2.9 (0.66)		2.6 (1.7)	
No	2.1 (0.70)		1.0 (0.98)	
Get answers to diabetes questions		<.001		<.001
Yes	3.0 (0.65)		2.7 (1.6)	
No	2.2 (0.67)		1.4 (1.4)	
Learn about potential side effects of drugs or devices		<.001		<.001
Yes	3.0 (0.65)		2.8 (1.6)	
No	2.3 (0.68)		1.5 (1.4)	
Learn things that my healthcare provider didn’t know		<.001		<.001
Yes	3.0 (0.68)		2.8 (1.6)	
No	2.4 (0.70)		1.5 (1.4)	
Learn strategies to improve insurance coverage for diabetes-related medications or supplies or tools		<.001		.003
Yes	3.0 (0.66)		2.7 (1.7)	
No	2.5 (0.72)		2.0 (1.6)	
Discussed a topic learned from DOC with my healthcare provider		<.001		<.001
Yes	3.0 (0.68)		3.2 (1.6)	
No	2.5 (0.68)		1.6 (1.4)	
Help others		<.001		<.001
Yes	2.9 (0.66)		2.7 (1.6)	
No	2.1 (0.74)		0.70 (0.88)	

Diabetes Online Community Intensity

The average DOC intensity scale score was 2.76 (SD .73) on a scale of 0 to 5. There was a difference in the intensity with which participants were using the DOC when comparing the 4 diabetes treatments ($F_{3,177}$=3.5, *P*=.02). Respondents who were on no medications (mean 3.1, SD 0.80) or on intensive insulin management (mean 2.8, SD 0.71) had higher DOC intensity scores when compared with those taking oral agents only (mean 2.3, SD 0.69). DOC intensity scores varied based on whether or not DOC users had told their healthcare providers about their DOC use, and if it was supported ($F_{3,170}$=11.3, *P*<.001). Specifically, DOC intensity scores were higher in those participants who had told their healthcare providers about their DOC use and felt supported (mean 3.2, SD 0.64) or were not sure (mean 3.2, SD 0.57) than those who had never told their healthcare providers about their DOC use at all (mean 2.6, SD 0.71). Type of diabetes or length of time using the DOC was not associated with DOC intensity. DOC intensity and DOC engagement were positively correlated (*r*=.572, *P*<.001).

Diabetes Online Community Engagement

The average DOC engagement score was 2.24 (SD 1.69) on a scale of 0 to 5. DOC engagement scores were related to healthcare provider knowledge and support of DOC use ($F_{3,170}$=11.0, *P*<.001). DOC engagement scores were higher for those who had told their healthcare providers about their DOC use and were unsure if they were supported (mean 2.9, SD 1.3) or felt supported (mean 3.6, SD 1.4) than for those who had never told their healthcare providers about their DOC use at all (mean 1.9, SD 1.6). DOC engagement scores were higher the longer someone had participated in the DOC. Those who had participated in the DOC for 4 or more years (mean 2.86, SD 1.7) were more engaged than those who had participated for less than 3 months (mean 1.50, SD 1.5, *P*<.001). There was no difference in DOC engagement scores for those who were insured or uninsured or by type of diabetes. Furthermore, there was no correlation between DOC engagement and age, diabetes type, or diabetes duration.

Health-Related Quality of Life

The SF-12v2 physical component summary mean score was 64.8 (SD 19) and the mental component mean summary score was 66.57 (SD 21.1); both were higher (*P*<.001, one sample *t* test) than previously reported physical component summary norms of individuals with diabetes [46]. The SF-12v2 physical component summary score negatively correlated with age (*r*=−.177, *P*=.02). The physical component summary and mental component summary were not related to diabetes type, DOC engagement, and DOC intensity.

Diabetes Self-Care Behaviors

On average, DOC participants had high self-care scores (mean 72.4, SD 12.0) compared with mean scores found in other samples of adults with type 1 and type 2 diabetes (*P*<.001, one-sample *t* test) [47]. Diabetes self-care behavior scores were lower in those who reported depression (reported depression mean 68.9, SD 13.8; reported no depression mean 74.1, SD 10.8, *P*=.007). There were positive correlations between self-care scores and DOC engagement scores (*r*=.170, *P*=.02), DOC intensity scores (*r*=.236, *P*=.002), and SF-12v2 mental component summary scores (*r*=.301, *P*<.001). There was a negative correlation between self-care scores and HbA_{1c} (*r*=−.157, *P*=.04). Correlation between diabetes self-care, HRQoL, DOC intensity, and DOC engagement is noted in Table 4.

Glycated Hemoglobin A1c Levels and Predictors

The majority (59.6%, 109/183) of survey respondents reported an HbA_{1c}<7%. There was no difference in HbA_{1c} levels between US users and non-US users, insured and uninsured users, or type of diabetes. After conducting an initial stepwise logistic regression, the final predictive binary logistic regression model (see Table 5) was employed to explain the HbA_{1c} category of <7% or ≥7% while controlling for all other variables in the model. The odds ratio for age was significant, with every 1-year increase in age yielding 34% reduction in the odds of having an HbA_{1c}≥7%. Diabetes duration generated a 1.46 odds ratio of having an HbA_{1c}≥7%. DOC engagement was a strong predictor of HbA_{1c} level; every single point increase in DOC engagement yielded a 33.8% reduction in the odds of an individual having an HbA_{1c}≥7%. There was a 2.7 times increase in the odds of having an HbA_{1c}≥7% among participants who reported that DOC helped them learn about strategies to improve insurance coverage for diabetes-related medications, supplies, and technology devices (coded yes or no).

Table 4. Correlation matrix for health indicators.

Health Indicator		1	2	3	4	5
1	DOC[a] intensity	1.00				
2	DOC engagement	.572[c]	1.00			
3	Physical HRQoL[b]	−.043	.102	1.00		
4	Mental HRQoL	−.076	.074	.651[c]	1.00	
5	Diabetes self-care	.236[d]	.170[e]	.097	.301[d]	1.00

[a] DOC: diabetes online community.

[b] HRQoL: health-related quality of life.

[c] Significance at the <.001 level.

[d] Significance at the <.01 level.

Table 5. Final model explaining risk of glycated hemoglobin $A_{1c}\geq7\%$.

Variable	Beta	SE	*P* value[a]	Exp (B)=odds ratio	95% CI for Exp (B)
DOC[b] engagement[c]	−.413	.132	.002	0.662	0.511-0.857
Diabetes diagnosis duration[d]	.377	.108	<.001	1.459	1.180-1.803
Learned insurance coverage strategies	.987	.406	.02	2.684	1.212-5.944
Help others	−.952	.557	.09	0.386	.0130-1.150
Support through rough times	.808	.441	.07	2.243	0.946-5.320
Age in years	−.035	.014	.01	.966	0.940-0.992
Constant	.349	.793	.66	1.417	

[a] *P* value of Wald ratio.

[b] DOC: diabetes online community.

[c] Mean score of 5 dichotomous variables, coded 0 to 5.

[d] Length of time in years since diabetes diagnosis using a square root transformation to address a positive skew.

Discussion

The purpose of this study was to explore who uses the DOC, how they use it, and whether DOC use is associated with specific health indicators. Below we discuss the significant findings that support both the importance of the DOC for specific populations with diabetes and the positive association of DOC use with health indicators. We also discuss implications for clinical practice.

Principal Findings

We found an overwhelming representation of type 1 diabetes within this sample of DOC users, even though type 1 diabetes makes up only 5% to 10% of all diagnosed cases of diabetes [55]. This overrepresentation may be due to the fact that one of our recruitment sites, TuDiabaetes, had mostly individuals with type 1 diabetes using their website. An alternative explanation is that individuals with type 1 diabetes must utilize intensive insulin management techniques, whereas individuals with type 2 diabetes may not. Intensive insulin management may drive an additional need for knowledge and support, leading patients to DOC. Furthermore, those with type 1 diabetes have more exposure to technology, given that they typically are diagnosed much younger and typically use a glucometer. Those with type 1 diabetes in this sample were younger and potentially more likely to use social media in general [56]. Finally, because there are fewer individuals with type 1 diabetes compared with type 2 diabetes in the general population, those with type 1 diabetes may not be able to connect with another person with their same condition offline and this may lead them to seek others like themselves online [2]. Diabetes research conducted in other online communities, such as PatientsLikeMe, have found more respondents with type 2 diabetes, suggesting that other factors such as DOC site user characteristics and site purpose may influence who participates [57]. There was no significant difference between type of diabetes as it related to DOC engagement or HbA_{1c}.

The majority of the participants had not told their healthcare providers about their DOC use. Although our findings support the idea that DOC use is supplementary to, not in place of, regular healthcare provider visits, research has shown that healthcare providers may be hesitant to suggest DOC use due to concerns about misinformation [58,59], fear of a power imbalance from the traditional hierarchy of medicine [60,61], or fear of a challenge to their authority [62]. It is important for healthcare providers to be aware of the DOC and how health-related social media is driving a more patient-centered healthcare system [63,64] by putting the patient's preferences and values about how they want to receive healthcare front and center [65], consistent with the eHealth-enhanced chronic care model [66]. Furthermore, healthcare providers should be learning how they can engage with DOC themselves while supporting their patients with diabetes to use the DOC [28,31,67]. If healthcare providers discuss and support DOC use with their patients, patients may be encouraged to access quality online diabetes self-care information and support. In this way, the DOC could be a complementary resource for information to support health literacy not found in the traditional healthcare model.

DOC intensity varied by treatment. Those with no medications or on intensive insulin management used DOC more intensely than those on oral agents. This is perhaps due to the fact that individuals on no medications may be accessing the DOC to educate themselves with hopes of halting the progression of their diabetes, whereas those on intensive insulin management require more education, skills, and support to manage their diabetes than those on oral agents only. Similar to other research, our study found associations between intensity of DOC use and feeling supported in disease management [68]. We did not find differences in DOC intensity between insured and uninsured participants; conversely, other research has shown that individuals with chronic conditions who were uninsured were more likely than those who were privately insured to be frequent users of online health information [69].

Our research indicates that DOC users have higher HRQoL when compared with HRQoL norms for the general population [46]. Individuals who seek online health information report being happier and healthier when compared with those who seek offline health information [70]. DOC users can quickly access health-related information they desire in multiple formats (ie, discussion board, blog, Tweetchat, etc), allowing them to easily review crowdsourced information from individuals living with diabetes, learn the same information in a variety of ways [8] from different DOC users to address learning style preferences, and focus on topics based on need and interest. The ability to obtain health information from the DOC in multiple ways supports a patient-centered approach to enhancing health literacy. The DOC also provides an avenue for individuals with diabetes to provide social support to one another. Social support, which has been linked to HRQoL scores [71], allows individuals to feel less alone in their diabetes. Individuals reported a sense of social connectedness, which strongly predicts altruism [72]. Altruism has been identified as a factor in participating in chronic disease online communities [73-75], which may enhance the social learning process.

This is the first study to demonstrate that engaging in the DOC is associated with positive health benefits for people with diabetes. DOC engagement is related to better glycemic levels, diabetes self-care, and HRQoL. DOC engagement allows individuals to share personal experiences, exchange emotional support, and gain expertise in day-to-day management techniques through crowdsourced information by peers. Although it is important to note that directionality and causation cannot be determined in this model, there is evidence to suggest that DOC engagement may lead to improved HbA_{1c} levels. Individuals who have an HbA_{1c}≥7% and longer diabetes duration may be engaging in the DOC to connect with others due to diabetes burnout. Furthermore, individuals who already had an HbA_{1c}≥7% may have sought support from the DOC to learn strategies to improve insurance coverage of diabetes-related expenses so they could in turn improve their diabetes management. Longitudinal research is necessary to understand glycemic levels as it relates to specifics of DOC use, such as learning how to improve insurance coverage for diabetes-related expenses.

Individuals with diabetes who are actively engaging in the DOC are actively participating in their own healthcare. Patient activation, known to decrease healthcare costs, is gauged by knowledge, skills, and confidence one has to manage his or her own health [76], which is associated with engagement in online communities [77]. In this study, DOC engagement was associated with increasing diabetes-related knowledge and skills, self-care, and empowerment, supporting the notion of high patient activation. Health literacy may also improve with increased diabetes-related knowledge. Research has shown that the interaction between patient activation and health literacy is associated with better glycemic levels [78]. Furthermore, patients who actively participate in medical decisions have improved glycemic levels [79]. Additional research is needed to distinctly identify how DOC impacts glycemic levels, patient activation, and health literacy.

DOC engagement was higher for DOC users whose healthcare providers supported them in their DOC use. Although it is important to note that a causal inference cannot be made, this finding has potential clinical implications in that DOC engagement may supplement current diabetes care and lead to improved glycemic levels. Participation in the DOC requires no resource allocation from the current healthcare system, although it is only available to those with internet access and a sufficient level of health literacy to use it. Despite documented benefits of face-to-face peer health [11-13,80], there are currently no professional recommendations for individuals to use peer health via the DOC to supplement their diabetes care.

Limitations

We recruited our sample from the DOC, and therefore, caution must be exercised when generalizing because of the possibility of bias due to sample self-selection. Individuals who responded to the survey may be more engaged with the DOC or have better glycemic levels. The majority of individuals in this sample identified themselves as using intensive insulin management, which does not reflect the treatment intensity seen in the general population. We had a response rate of 12.2% based on the number of times the study recruitment post was viewed by unique site visitors. Although the recruitment percentage may appear low, a response rate of <.1% is not unusual for online surveys [81]. The respondents were overwhelmingly white, college-educated females living in the United States, which may not be an accurate reflection of the entire DOC population, and is not an accurate reflection of the general population with diabetes. For example, individuals who are American Indian or Alaskan Native, black, and Hispanic are more likely to have diabetes than those who are white [82]. Finally, this study only looked at adult DOC users, and findings should not be generalized to individuals with gestational diabetes, minors, or caregivers participating in the DOC.

Self-reporting of HbA_{1c} may affect reliability of data; however, research that validated self-reported HbA_{1c} with laboratory values has shown that self-reported diabetes data are accurate >92% of the time [83]. Similar HbA_{1c} results have been found among international DOC users, in which the average HbA_{1c} was 6.9% [84]. In addition, some DOC participants have been found to share their HbA_{1c} levels with others online [84], and have gone as far as including a photograph of their lab record. Transparency in sharing health information, as seen in recent #wearenotwaiting and #OpenAPS movements on Twitter and other social media sites [85], may improve reliability in reporting, although we did not request HbA_{1c} documentation for this study.

The nature of this research cannot determine causality. We do not know if the high DOC engagement results in high self-care and optimal glycemic levels, or vice versa, or if common unknown causal factors induce the association. Prospective studies, specifically randomized control trials, are warranted to better understand DOC and its impact on health outcomes.

Conclusions

Our study found that higher engagement with the DOC was associated with HbA_{1c} levels <7%, although we cannot determine directionality of this relationship. We also found that DOC users are generally proactive in diabetes self-care behaviors and that there was a strong sense of community among DOC participants. Participants found DOC peer health to be beneficial with regard to knowledge attainment and support, factors known to enhance health literacy. Our survey indicated that DOC users are often not informing their healthcare providers about their participation with the DOC. Our findings suggest that healthcare providers should be familiar with DOC and ask their patients about use of online sources for diabetes self-care information and support. Supplementing usual healthcare activities with DOC use may encourage knowledge and support among a population that can benefit greatly from optimizing diabetes self-care. This study adds to the body of knowledge in diabetes care and online communities for chronic disease management. Further studies to determine how DOC use affects health outcomes, and how health behaviors contagiously spread throughout the DOC, would be enlightening.

Acknowledgments

This research was supported by predoctoral grants from the Jonas Center for Nursing Excellence/John A. Hartford Center and the Noorda Family Foundation/University of Utah Hartford Center of Geriatric Nursing Excellence. Additionally, this work was supported by a research grant from Sigma Theta Tau International, Nu Nu Chapter. The authors would like to acknowledge the other members of Litchman's dissertation committee: Ginny Pepper, Joy Pierce, Scott Wright, and Erin Rothwell; and the key informants within the diabetes online community who made this study possible. The authors would also like to thank Holly Witteman, PhD, who edited an earlier version of this manuscript.

Conflicts of Interest

None declared.

References

1. Fox S. The Social Life of Health Information, 2011. Pew Research Center. 2011. Health topics URL: http://www.pewinternet.org/2011/05/12/health-topics/[WebCite Cache ID 6xx5tRYH3]
2. Fox S. Peer-to-peer healthcare. Pew Research Center. 2011. URL: http://www.pewinternet.org/2011/02/28/peer-to-peer-health-care-2/[WebCite Cache ID 6xx5yKMXp]
3. Eysenbach G. Medicine 2.0: social networking, collaboration, participation, apomediation, and openness. J Med Internet Res 2008;10(3):e22 [FREE Full text] [doi: 10.2196/jmir.1030] [Medline: 18725354]
4. US Department of Health and Human Services. Health.gov. Washington, DC: Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services; 2006. Expanding the reach and impact of consumer e-health tools URL: https://health.gov/communication/ehealth/ehealthTools/default.htm [accessed 2018-03-24] [WebCite Cache ID 6yAi7V31c]
5. Rubenstein EL. Crowdsourcing health literacy: the case of an online community. 2013 Presented at: Proceedings of the 76th ASIS&T Annual Meeting: Beyond the Cloud: Rethinking Information Boundaries; November 1-5, 2013; Montreal, Quebec, Canada p. 1-5. [doi: 10.1002/meet.14505001119]
6. Willis E. The making of expert patients: the role of online health communities in arthritis self-management. J Health Psychol 2014 Dec;19(12):1613-1625 [FREE Full text] [doi: 10.1177/1359105313496446] [Medline: 23988679]
7. Eysenbach G. What is e-health? J Med Internet Res 2001;3(2):E20 [FREE Full text] [doi: 10.2196/jmir.3.2.e20] [Medline: 11720962]
8. Korda H, Itani Z. Harnessing social media for health promotion and behavior change. Health Promot Pract 2013 Jan;14(1):15-23. [doi: 10.1177/1524839911405850] [Medline: 21558472]
9. Brownson CA, Heisler M. The role of peer support in diabetes care and self-management. Patient 2009 Mar 01;2(1):5-17. [doi: 10.2165/01312067-200902010-00002] [Medline: 22273055]

10. Fisher EB, Boothroyd RI, Coufal MM, Baumann LC, Mbanya JC, Rotheram-Borus MJ, et al. Peer support for self-management of diabetes improved outcomes in international settings. Health Aff 2012 Jan;31(1):130-139 [FREE Full text] [doi: 10.1377/hlthaff.2011.0914] [Medline: 22232103]
11. Lorig K, Ritter PL, Villa FJ, Armas J. Community-based peer-led diabetes self-management: a randomized trial. Diabetes Educ 2009;35(4):641-651. [doi: 10.1177/0145721709335006] [Medline: 19407333]
12. Heisler M, Piette JD. "I help you, and you help me": facilitated telephone peer support among patients with diabetes. Diabetes Educ 2005;31(6):869-879. [doi: 10.1177/0145721705283247] [Medline: 16288094]
13. Heisler M, Vijan S, Makki F, Piette JD. Diabetes control with reciprocal peer support versus nurse care management: a randomized trial. Ann Intern Med 2010 Oct 19;153(8):507-515 [FREE Full text] [doi: 10.7326/0003-4819-153-8-201010190-00007] [Medline: 20956707]
14. Brown SA, Garcia AA, Kouzekanani K, Hanis CL. Culturally competent diabetes self-management education for Mexican Americans: the Starr County border health initiative. Diabetes Care 2002 Feb;25(2):259-268 [FREE Full text] [Medline: 11815493]
15. Lujan J, Ostwald SK, Ortiz M. Promotora diabetes intervention for Mexican Americans. Diabetes Educ 2007;33(4):660-670 [FREE Full text] [doi: 10.1177/0145721707304080] [Medline: 17684167]
16. Lorig K, Ritter PL, Laurent DD, Plant K, Green M, Jernigan VB, et al. Online diabetes self-management program: a randomized study. Diabetes Care 2010 Jun;33(6):1275-1281 [FREE Full text] [doi: 10.2337/dc09-2153] [Medline: 20299481]
17. Ayala GX, Ibarra L, Cherrington AL, Parada H, Horton L, Ji M, et al. Puentes hacia una mejor vida (Bridges to a Better Life): outcome of a diabetes control peer support intervention. Ann Fam Med 2015 Aug;13 Suppl 1:S9-17 [FREE Full text] [doi: 10.1370/afm.1807] [Medline: 26304977]
18. Moore K, Mengel M. Expanding the team: the use of volunteers in a diabetes education program. Diabetes Educ 2002;28(4):554-8, 560, 562 [FREE Full text] [doi: 10.1177/014572170202800409] [Medline: 12224195]
19. Gilmer TP, Philis-Tsimikas A, Walker C. Outcomes of Project Dulce: a culturally specific diabetes management program. Ann Pharmacother 2005 May;39(5):817-822. [doi: 10.1345/aph.1E583] [Medline: 15769828]
20. Liebman J, Heffernan D, Sarvela P. Establishing diabetes self-management in a community health center serving low-income Latinos. Diabetes Educ 2007 Jun;33 Suppl 6:132S-138S [FREE Full text] [doi: 10.1177/0145721707304075] [Medline: 17620392]
21. Thompson JR, Horton C, Flores C. Advancing diabetes self-management in the Mexican American population: a community health worker model in a primary care setting. Diabetes Educ 2007 Jun;33 Suppl 6:159S-165S [FREE Full text] [doi: 10.1177/0145721707304077] [Medline: 17620396]
22. Two Feathers J, Kieffer EC, Palmisano G, Anderson M, Sinco B, Janz N, et al. Racial and Ethnic Approaches to Community Health (REACH) Detroit partnership: improving diabetes-related outcomes among African American and Latino adults. Am J Public Health 2005 Sep;95(9):1552-1560. [doi: 10.2105/AJPH.2005.066134] [Medline: 16051927]
23. Markowitz JT, Laffel LM. Transitions in care: support group for young adults with Type 1 diabetes. Diabet Med 2012 Apr;29(4):522-525 [FREE Full text] [doi: 10.1111/j.1464-5491.2011.03537.x] [Medline: 22150392]
24. Philis-Tsimikas A, Fortmann A, Lleva-Ocana L, Walker C, Gallo LC. Peer-led diabetes education programs in high-risk Mexican Americans improve glycemic control compared with standard approaches: a Project Dulce promotora randomized trial. Diabetes Care 2011 Sep;34(9):1926-1931 [FREE Full text] [doi: 10.2337/dc10-2081] [Medline: 21775748]
25. Funnell MM, Brown TL, Childs BP, Haas LB, Hosey GM, Jensen B, et al. National standards for diabetes self-management education. Diabetes Care 2012 Jan;35 Suppl 1:S101-S108 [FREE Full text] [doi: 10.2337/dc12-s101] [Medline: 22187467]
26. Beck J, Greenwood DA, Blanton L, Bollinger ST, Butcher MK, Condon JE, 2017 Standards Revision Task Force. 2017 National Standards for Diabetes Self-Management Education and Support. Diabetes Educ 2018 Feb;44(1):35-50. [doi: 10.1177/0145721718754797] [Medline: 29346744]
27. Litchman ML, Rothwell E, Edelman LS. The diabetes online community: older adults supporting self-care through peer health. Patient Educ Couns 2018;101(3):518-523. [doi: 10.1016/j.pec.2017.08.023] [Medline: 28947360]
28. Cooper A, Kar P. A new dawn: the role of social media in diabetes education. J Diabetes Nurs 2014;18(2):68-71 [FREE Full text]
29. Farrell H. Diabetes Online Community #DOC. Nurs Gen Pract 2014;7(4):8-10.
30. Shaffer-Hudkins E, Johnson N, Melton S, Wingert A. Social media use among individuals with diabetes. Int J Commun Health 2014;4:38-43 [FREE Full text]
31. Collins SE, Lewis DM. Social media made easy: Guiding patients to credible online health information and engagement resources. Clinical Diabetes 2013;31(3):137-141. [doi: 10.2337/diaclin.31.3.137]
32. Sparud-Lundin C, Ranerup A, Berg M. Internet use, needs and expectations of web-based information and communication in childbearing women with type 1 diabetes. BMC Med Inform Decis Mak 2011 Jul 07;11:49 [FREE Full text] [doi: 10.1186/1472-6947-11-49] [Medline: 21736713]
33. Armstrong N, Powell J. Patient perspectives on health advice posted on Internet discussion boards: a qualitative study. Health Expect 2009 Sep;12(3):313-320. [doi: 10.1111/j.1369-7625.2009.00543.x] [Medline: 19555377]
34. Jennings A, Powell J, Armstrong N, Sturt J, Dale J. A virtual clinic for diabetes self-management: pilot study. J Med Internet Res 2009;11(1):e10 [FREE Full text] [doi: 10.2196/jmir.1111] [Medline: 21821504]

35. Armstrong N, Koteyko N, Powell J. 'Oh dear, should I really be saying that on here?': issues of identity and authority in an online diabetes community. Health (London) 2012 Jul;16(4):347-365. [doi: 10.1177/1363459311425514] [Medline: 22067915]
36. Greene JA, Choudhry NK, Kilabuk E, Shrank WH. Online social networking by patients with diabetes: a qualitative evaluation of communication with Facebook. J Gen Intern Med 2011 Mar;26(3):287-292 [FREE Full text] [doi: 10.1007/s11606-010-1526-3] [Medline: 20945113]
37. Ravert RD, Hancock MD, Ingersoll GM. Online forum messages posted by adolescents with type 1 diabetes. Diabetes Educ 2004;30(5):827-834. [doi: 10.1177/014572170403000518] [Medline: 15510534]
38. Zhou X, Sun S, Yang J. Sweet Home: Understanding diabetes management via a Chinese online community. 2014 Presented at: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems; April 26 - May 1, 2014; Toronto, Ontario, Canada p. 3997-4006. [doi: 10.1145/2556288.2557344]
39. Gilbert K, Dodson S, Gill M, McKenzie R. Online communities are valued by people with type 1 diabetes for peer support: how well do health professionals understand this? Diabetes Spectrum 2012 Aug 15;25(3):180-191. [doi: 10.2337/diaspect.25.3.180]
40. Oh HJ, Lee B. The effect of computer-mediated social support in online communities on patient empowerment and doctor-patient communication. Health Commun 2012;27(1):30-41. [doi: 10.1080/10410236.2011.567449] [Medline: 21797714]
41. Zrebiec JF, Jacobson AM. What attracts patients with diabetes to an internet support group? A 21-month longitudinal website study. Diabet Med 2001 Feb;18(2):154-158. [Medline: 11251681]
42. Zrebiec JF. Internet communities: do they improve coping with diabetes? Diabetes Educ 2005;31(6):825-8, 830-2, 834, 836. [doi: 10.1177/0145721705282162] [Medline: 16288090]
43. Hilliard ME, Sparling KM, Hitchcock J, Oser TK, Hood KK. The emerging diabetes online community. Curr Diabetes Rev 2015;11(4):261-272 [FREE Full text] [Medline: 25901500]
44. Hoffman-Goetz L, Donelle L, Thomson MD. Clinical guidelines about diabetes and the accuracy of peer information in an unmoderated online health forum for retired persons. Inform Health Soc Care 2009 Mar;34(2):91-99. [doi: 10.1080/17538150902865136] [Medline: 19412842]
45. Cole J, Watkins C, Kleine D. Health advice from Internet discussion forums: how bad is dangerous? J Med Internet Res 2016 Jan 06;18(1):e4 [FREE Full text] [doi: 10.2196/jmir.5051] [Medline: 26740148]
46. Ware JE, Kosinski M, Turner-Bowker DM, Gandek B. User's Manual for the SF-12v2 Health Survey. Lincoln, Rhode Island: QualityMetric Incorporated; 2007.
47. Weinger K, Butler HA, Welch GW, La Greca AM. Measuring diabetes self-care: a psychometric analysis of the Self-Care Inventory-Revised with adults. Diabetes Care 2005 Jun;28(6):1346-1352 [FREE Full text] [Medline: 15920050]
48. Ware JE, Kosinski M, Turner-Bowker DM, Gandek B. How to Score Version 2 of the SF-12 Health Survey. Lincoln, RI: QualityMetric Incorporated; 2002.
49. Ellison NB, Steinfield C, Lampe C. The benefits of Facebook “friends”: social capital and college students' use of online social network sites. J Comput Mediat Commun 2007;12(4):1143-1168. [doi: 10.1111/j.1083-6101.2007.00367.x]
50. Williams D. On and off the 'net: scales for social capital in an online era. J Comput Mediat Commun 2006 Jan;11(2):593-628. [doi: 10.1111/j.1083-6101.2006.00029.x]
51. McCroskey JC, Teven JJ. Goodwill: a reexamination of the construct and its measurement. Commun Monogr 1999;66(1):90-103. [doi: 10.1080/03637759909376464]
52. Hernandez M. dLife. 2011. Ten reasons why you should join a diabetes social network URL: http://dlife.com/diabetes/type-1/manny_hernandez/join-a-diabetes-social-network [accessed 2018-03-16] [WebCite Cache ID 6xx6zdjLM]
53. IBM Corp. IBM SPSS Statistics for Windows. Version 21.0 ed. Armonk, NY: IBM Corp; 2012.
54. American Diabetes Association. Standards of Medical Care in Diabetes-2016 Abridged for Primary Care Providers. Clin Diabetes 2016 Jan;34(1):3-21 [FREE Full text] [doi: 10.2337/diaclin.34.1.3] [Medline: 26807004]
55. US Department of Health & Human Services, National Diabetes Information Clearinghouse. Diabetes in America, 2nd ed. Washington, DC: National Institute of Diabetes and Digestive and Kidney Diseases; 2014.
56. Greenwood S, Perrin A, Duggan M. Pewinternet.: Pew Research Center: Pew Research Center's Internet and American Life Project; 2016. Social Media Update 2016 URL: http://www.pewinternet.org/2016/11/11/social-media-update-2016/ [accessed 2018-03-16] [WebCite Cache ID 6xx7Sm4mB]
57. Schroeder EB, Desai J, Schmittdiel JA, Paolino AR, Schneider JL, Goodrich GK, et al. An innovative approach to informing research: gathering perspectives on diabetes care challenges from an online patient community. Interact J Med Res 2015 Jun;4(2):e13 [FREE Full text] [doi: 10.2196/ijmr.3856] [Medline: 26126421]
58. Ahmad F, Hudak PL, Bercovitz K, Hollenberg E, Levinson W. Are physicans ready for patients with internet-based health information? J Med Internet Res 2006 Sep 29;8(3):e22. [doi: 10.2196/jmir.8.3.e22]
59. Moick M, Terlutter R. Physicians' motives for professional internet use and differences in attitudes toward the internet-informed patient, physician-patient communication, and prescribing behavior. Med 2 0 2012 Jul;1(2):e2 [FREE Full text] [doi: 10.2196/med20.1996] [Medline: 25075230]

60. Snow R, Humphrey C, Sandall J. What happens when patients know more than their doctors? Experiences of health interactions after diabetes patient education: a qualitative patient-led study. Br Med J Open 2013 Nov 14;3(11):e003583 [FREE Full text] [doi: 10.1136/bmjopen-2013-003583] [Medline: 24231459]
61. Murray E, Pollack L, White M, Lo B. Clinical decision-making: physicians' preferences and experiences. BMC Fam Pract 2007 Mar 15;8:10 [FREE Full text] [doi: 10.1186/1471-2296-8-10] [Medline: 17362517]
62. Murray E, Lo B, Pollack L, Donelan K, Catania J, Lee K, et al. The impact of health information on the Internet on health care and the physician-patient relationship: National U.S. survey among 1050 U.S. physicians. J Med Internet Res 2003;5(3):e17 [FREE Full text] [doi: 10.2196/jmir.5.3.e17] [Medline: 14517108]
63. van der Eijk M, Faber MJ, Aarts JW, Kremer JA, Munneke M, Bloem BR. Using online health communities to deliver patient-centered care to people with chronic conditions. J Med Internet Res 2013 Jun;15(6):e115 [FREE Full text] [doi: 10.2196/jmir.2476] [Medline: 23803284]
64. Hawn C. Take two aspirin and tweet me in the morning: how Twitter, Facebook, and other social media are reshaping health care. Health Aff (Millwood) 2009;28(2):361-368 [FREE Full text] [doi: 10.1377/hlthaff.28.2.361] [Medline: 19275991]
65. Institute of Medicine Committee on Quality of Health Care in America. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington (DC): National Academies Press (US); 2001.
66. Gee PM, Greenwood DA, Paterniti DA, Ward D, Miller LM. The eHealth Enhanced Chronic Care Model: a theory derivation approach. J Med Internet Res 2015;17(4):e86 [FREE Full text] [doi: 10.2196/jmir.4067] [Medline: 25842005]
67. Smith SM, Paul G, Kelly A, Whitford DL, O'Shea E, O'Dowd T. Peer support for patients with type 2 diabetes: cluster randomised controlled trial. Br Med J 2011 Feb 15;342:d715 [FREE Full text] [Medline: 21324992]
68. Cobb NK, Graham AL, Bock BC, Papandonatos G, Abrams DB. Initial evaluation of a real-world Internet smoking cessation system. Nicotine Tob Res 2005 Apr;7(2):207-216 [FREE Full text] [doi: 10.1080/14622200500055319] [Medline: 16036277]
69. Bundorf MK, Wagner TH, Singer SJ, Baker LC. Who searches the internet for health information? Health Serv Res 2006 Jun;41(3 Pt 1):819-836 [FREE Full text] [doi: 10.1111/j.1475-6773.2006.00510.x] [Medline: 16704514]
70. Cotten SR, Gupta SS. Characteristics of online and offline health information seekers and factors that discriminate between them. Soc Sci Med 2004 Nov;59(9):1795-1806. [doi: 10.1016/j.socscimed.2004.02.020] [Medline: 15312915]
71. Aalto AM, Uutela A, Aro AR. Health related quality of life among insulin-dependent diabetics: disease-related and psychosocial correlates. Patient Educ Couns 1997 Mar;30(3):215-225. [Medline: 9104378]
72. Putnam R. Social capital: measurement and consequences. Can J Policy Res 2001;2(1):41-51.
73. Reeves D, Blickem C, Vassilev I, Brooks H, Kennedy A, Richardson G, et al. The contribution of social networks to the health and self-management of patients with long-term conditions: a longitudinal study. PLoS One 2014;9(6):e98340 [FREE Full text] [doi: 10.1371/journal.pone.0098340] [Medline: 24887107]
74. Oh S. The characteristics and motivations of health answerers for sharing information, knowledge, and experiences in online environments. J Am Soc Inf Sci 2011 Nov 01;63(3):543-557. [doi: 10.1002/asi.21676]
75. van Uden-Kraan F, Drossaert CH, Taal E, Shaw BR, Seydel ER, van de Laar MA. Empowering processes and outcomes of participation in online support groups for patients with breast cancer, arthritis, or fibromyalgia. Qual Health Res 2008 Mar;18(3):405-417. [doi: 10.1177/1049732307313429] [Medline: 18235163]
76. Hibbard JH, Greene J, Overton V. Patients with lower activation associated with higher costs; delivery systems should know their patients' 'scores'. Health Aff 2013 Feb;32(2):216-222. [doi: 10.1377/hlthaff.2012.1064] [Medline: 23381513]
77. Grosberg D, Grinvald H, Reuveni H, Magnezi R. Frequent surfing on social health networks is associated with increased knowledge and patient health activation. J Med Internet Res 2016 Aug 10;18(8):e212 [FREE Full text] [doi: 10.2196/jmir.5832] [Medline: 27511272]
78. Woodard LD, Landrum CR, Amspoker AB, Ramsey D, Naik AD. Interaction between functional health literacy, patient activation, and glycemic control. Patient Prefer Adherence 2014;8:1019-1024 [FREE Full text] [doi: 10.2147/PPA.S63954] [Medline: 25092966]
79. Greenfield S, Kaplan SH, Ware Jr JE, Yano EM, Frank HJ. Patients' participation in medical care: effects on blood sugar control and quality of life in diabetes. J Gen Intern Med 1988;3(5):448-457. [Medline: 3049968]
80. Rashidi K, Safavi M, Yahyavi H, Farahani H. The impact of peers' support on the hemoglobin A1C and fasting blood sugar level of patients with type 2 diabetes. Indian J Med Spec 2017;8(1):7-12. [doi: 10.1016/j.injms.2016.10.001]
81. Eysenbach G. Improving the quality of Web surveys: the Checklist for Reporting Results of Internet E-Surveys (CHERRIES). J Med Internet Res 2004 Dec 29;6(3):e34 [FREE Full text] [doi: 10.2196/jmir.6.3.e34] [Medline: 15471760]
82. Centers for Disease Control and Prevention. CDC. 2017. National Diabetes Statistics Report URL: https://www.cdc.gov/features/diabetes-statistic-report/index.html [accessed 2018-03-16] [WebCite Cache ID 6xx7ej9PG]
83. Schneider AL, Pankow JS, Heiss G, Selvin E. Validity and reliability of self-reported diabetes in the Atherosclerosis Risk in Communities Study. Am J Epidemiol 2012 Oct 15;176(8):738-743 [FREE Full text] [doi: 10.1093/aje/kws156] [Medline: 23013620]
84. Weitzman ER, Adida B, Kelemen S, Mandl KD. Sharing data for public health research by members of an international online diabetes social network. PLoS One 2011 Apr 27;6(4):e19256 [FREE Full text] [doi: 10.1371/journal.pone.0019256] [Medline: 21556358]

85. Omer T. Empowered citizen 'health hackers' who are not waiting. BMC Med 2016 Aug 17;14(1):118 [FREE Full text] [doi: 10.1186/s12916-016-0670-y] [Medline: 27530970]

Abbreviations

DOC: diabetes online community
HRQoL: health-related quality of life
LADA: Latent Autoimmune Diabetes of Adulthood
REDCap: Research Electronic Data Capture
SCI-R: Self-Care Inventory-Revised

Edited by G Eysenbach; submitted 29.07.17; peer-reviewed by P Gee, M Hilliard, T Oser, H Akram, T Bose; comments to author 15.09.17; revised version received 31.01.18; accepted 18.02.18; published 24.04.18

Please cite as:
Litchman ML, Edelman LS, Donaldson GW
Effect of Diabetes Online Community Engagement on Health Indicators: Cross-Sectional Study
JMIR Diabetes 2018;3(2):e8
URL: http://diabetes.jmir.org/2018/2/e8/
doi: 10.2196/diabetes.8603
PMID: 30291079