

Social Media Content Analysis of Public Diabetes Facebook Groups

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Abstract

Introduction: Relatively little is known about how Facebook groups are used to facilitate diabetes self-management support. This study provides a critical analysis of public diabetes Facebook groups and their content.

Methods: Two trained researchers independently identified 34 public Facebook diabetes groups. A coding and classification scheme was applied to the 20 most recent “wall posts” within 15 of the 34 (44.1%) largest groups ($n = 300$ posts). Nonparametric Mann-Whitney U tests examined differences in group characteristics between groups with more (active) and less (inactive) than 50 posts in the past month. Multivariable logistic regressions evaluated associations between group purpose, post types, membership (engagement leader vs regular user), and modality.

Results: We identified 193 458 members of the 34 largest diabetes Facebook groups (Mdn size = 3124 members, IQR = 1298–8523 members). Many groups (20/34, 58.8%) were created to provide instrumental support, while fewer (12/34, 35.8%) aimed to provide emotional support. Nutrition was the only diabetes self-management topic addressed in more than 30% of posts ($n = 107$). Posts made by engagement leaders were almost five times more likely to appear within inactive compared to active groups.

Discussion: Diabetes Facebook groups are used to share both information and emotional support, with greater emphasis placed on sharing information about nutrition. While engagement leaders should theoretically increase the credibility of online forums, frequent posts by group engagement leaders may actually lead to group decay. Health and diabetes educators should consider how to more effectively leverage social media engagement leaders to disseminate valid health information on diabetes self-management.

Keywords

diabetes, self-management, social media, support group

Over the past 20 years, the number of adults in the United States diagnosed with diabetes has more than tripled due to an aging population that is increasingly overweight and obese.¹ The prevalence of diabetes is also increasing in Europe, due to similar issues caused by unhealthy diets and sedentary lifestyles.² The World Health Organization (WHO) estimates that the number of diabetes-related deaths will double by 2030.^{2–4} While there is no cure for diabetes, self-management and a healthy lifestyle can help control the negative effects of diabetes on people’s everyday lives.¹

People living with diabetes express confidence using online technologies to access health information about self-management topics ranging from nutritional recommendations to treatment options.^{5–7} However, these patients are also concerned about the functionality and security of medical information shared via technology.^{8,9} Despite these concerns, people with diabetes are motivated to use and share health information across online social support networks.^{7,10} Online social networking facilitates peer-to-peer coping mechanisms

that can produce cost savings through access to enhanced self-management support,¹¹ even among medically underserved populations.¹² Online social networking also improves self-efficacy related to several diabetes self-management domains (eg, medication adherence).¹³

Although there is strong potential for popular online social networks to become an important motivational and communication tool for type 1 diabetes management,^{14,15} there is insufficient evidence regarding how different aspects of social media are being utilized to facilitate diabetes care.^{5,16} Facebook is one of the most commonly used social

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networking websites for connecting people with chronic disease.¹⁷ Consequently, health care organizations are beginning to utilize Facebook as an inexpensive tool for patient education on a variety of health topics.^{16,18} The “Groups” feature of Facebook provides a dedicated platform space for Facebook users to communicate about shared interests.¹⁹ Multimedia content posted to public Facebook group walls can be accessed by all Facebook users, but only group members can share information and reply to fellow group member comments.²⁰⁻²² While social networking groups such as these show strong potential for peer-to-peer health communication, there are challenges to administering chronic-disease-related Facebook groups that are both productive and acceptable to all members.²³

Only two prior studies have examined the purpose and select content of diabetes-related Facebook groups.^{24,25} In 2011, Greene and colleagues²⁵ found that diabetes-specific Facebook groups are most often used for information-sharing, patient-centered management, community-building, and marketing/data collection. More recently, Abedin et al²⁴ showed that Facebook groups provided educational support for individuals with diabetes and their caregivers by spreading valuable and reliable information about podiatric care. While both studies showed that users of these groups share relatively accurate information about self-management and diabetes-related medications, Greene et al’s²⁵ study was conducted approximately 10 years ago and Abedin et al²⁴ delimited their content analysis to groups only addressing foot care for people with diabetes.

Over the past decade, diabetes care recommendations have evolved significantly due to advances in medical treatments and self-management interventions.²⁶ Beyond the fact that emotional and informational support is generally provided within online contexts, there is a dearth of literature on mechanism(s) possibly driving user exchanges on public diabetes Facebook groups. For example, multimedia, unlike text, can reach individuals with low health literacy on social media through enhancing instructional message delivery of informational posts.²⁷ Social media can also reduce the layers of technological separation that often prevents computer-mediated social support.²⁸ Little is known about the actual content of public diabetes Facebook groups outside of podiatric care.²⁹ Specifically, there is little information on what message modalities are used and what types of social support (eg, instrumental, emotional) are provided within these groups. The purpose of this study is to explore which diabetes care practices are shared on public Facebook groups and how users communicate and engage with this information.

Methods

Search Procedures to Identify Public Diabetes Groups

In September 2018, two researchers independently entered the generic keyword “diabetes” into Facebook’s built-in

group search engine to find the largest public Facebook groups related to type 1 or type 2 diabetes. Examining groups with larger group membership provided a representative snapshot of the content and engagement a typical user would be exposed to. Searches were restricted to Facebook groups operated in English and those publicly accessible (labeled as “open” and “public”) to any person or entity with a valid Facebook account. Open groups were required to be for humans with type 1 or type 2 diabetes. The decision to only include groups with 20 or more wall posts within the past 12 months ensured that groups had more active engagement from group members. Furthermore, previous research on Facebook groups analyzed the 20 most recent wall posts.²² Limiting the analysis to the 20 most recent wall posts helped minimize bias toward groups with more posted content unlikely to be consumed by all members due to search/scrolling fatigue.³⁰ The decision to analyze wall posts from about one-half of largest remaining public diabetes Facebook groups (44.12%) is also consistent with sampling methods reported in similar studies.²⁵

Wall posts written in languages other than English were translated using Facebook’s “See Translation” link. Groups providing information on foot care for people with diabetes were excluded due to the recent review published by Abedin et al.²⁴ IRB approval for this study was secured prior to data collection.

Following IRB approval, the 50 largest public diabetes-related Facebook groups (with the most members) were initially identified. Ten groups were not in English, four contained <20 posts in the past 12 months, and one group was not in English and included <20 posts in the past 12 months. This resulted in 16 groups being removed, leaving 34 Facebook groups eligible for analysis.

Data Extraction

Two researchers independently reviewed a nonprobability sample of the remaining 34 largest public diabetes Facebook groups. Neither researcher was an administrator or member of any group that was reviewed. Using content analysis strategies adapted from methods used in prior Facebook group research,^{24,25} a coding and classification scheme was applied to the 20 most recent “wall posts” (comments and content uploaded by members on the main group page) within the 15 largest remaining groups (n = 300 posts). The primary focus of the coding and classification scheme was to extract data related to diabetes self-management education topics and communication patterns found on wall posts.

Coder Training

A coding rubric was developed based on existing content analyses of health-related Facebook groups.^{21,24,25} All potential codes were discussed in the context of diabetes self-management to operationalize and clarify specific codes.

Table 1. Facebook Group Content Analysis Codes, Definitions, and Code Sources.

Code	Definition	Code source
Group purpose		
Nonprofit fund-raising	Created to attract financial resources and donations for diabetes through an event, product or service	Greene et al ²⁵
Information sharing	Created to build awareness about self-management	Greene et al ²⁵
Social support/community Building	Created to meet the information, emotional, instrumental, or appraisal needs of people living with diabetes	Greene et al ²⁵
Promotional	Created to promote the sale of diabetes-related products or services	Greene et al ²⁵
Media modality		
Text	Text included in the post	Neiger et al ³²
Video	Video included in the post	Neiger et al ³²
Photo	Photo was included in the post	Neiger et al ³²
External weblink	External weblink was included in the post to redirect members to other websites, Facebook pages, videos, etc	Lerman et al ²¹
Communication patterns		
Self-disclosures	Information was self-disclosed about personal experiences with diabetes	Lerman et al ²¹
Mentions of self-management	Term “self-management” was used	N/A
Questions about self-management	Question was posed about diabetes-related topics	N/A
Educational content		
Blood glucose screening	Mentions blood glucose, blood sugar, etc	CDC ³³
Medication management	Mentions of medications to treat diabetes such as insulin, metformin, etc	CDC ³³
Nutrition	Mentions nutrition such as recipes, recommended dietary intake, etc	CDC ³³
Physical activity	Mentions physical activity such as walking, stair climbing, home bicycle, aerobics, etc	CDC ³³
Infection control	Mentions diabetes-related infections, infection control, management of infections, etc	CDC ³³
Recommended cures	Recommends a diabetes cure (herbal remedy, medical cure (eg, stem cell therapy), and/or religious/spiritual approach	N/A
Engagement		
Likes	Number of times members reacted to the post by pressing the thumbs up icon	Neiger et al ³²
Shares	Number of times people reacted to a post by sharing it	Neiger et al ³²
Comments	Number of times members reacted to a post by replying with text, gif, etc	Neiger et al ³²

Coders met to discuss issues and resolve any coding discrepancies prior to analysis. Discrepancies not meeting agreement were ultimately resolved by a third researcher. Two researchers coded 20 randomly selected wall posts from five Facebook Groups, which was sufficient for establishing intercoder reliability.³¹

Measures

Following coder training, data were extracted on group characteristics (eg, group name, number of assigned group administrators/moderators, diabetes type, and number of members) and deidentified. The purpose of each Facebook group and type of diabetes (1 or 2) was determined by reviewing the group title/description and information found in the “Recent News” section. Group reach was determined by recording the total number of members and number of members gained or lost in the past 30 days. The intensity of each group’s wall activity was measured by recording the number of posts made daily and over the past 30 days. In addition, the presence of an “engagement leader” in each group was evaluated. An engagement leader was operationally defined as a group member who

posted at least one-quarter (ie, 5) of the 20 most recent wall posts. Table 1 presents final codes and definitions used to analyze the purpose of each Facebook group, including the media modalities, communication patterns, and engagement metrics associated with diabetes self-management education content.

Data Analysis

Data collected was exported to SPSS v24.0 for analyses. Cohen’s kappa statistic^{34,35} was used to measure intercoder reliability. Frequency and descriptive statistics were calculated to summarize and compare the size and amount of user-generated contributions for each group. Nonparametric data led to reporting medians (\pm IQR). Spearman’s rho statistics were computed to determine associations between group membership characteristics. The Mann-Whitney *U* test was used to examine differences between “inactive” and “active” groups in terms of the number of group members, members gained during the last 30 days, number of administrators/moderators, and amount of time groups were in existence. Groups were “active” if they posted \geq 50 messages within the past month and “inactive” if $<$ 50 messages were posted.³⁶

Table 2. Intercoder Reliability Scores for Self-Management Content Areas and Characteristics of Diabetes Group Wall Posts ($n = 100$).

Self-management content area	Cohen's kappa
Blood glucose screening	.61
Medication management	.67
Infection control	.99
Nutrition	.69
Physical activity	.74
Mean	.74
SD	.15
Wall post characteristics	
Post included text	.99
Post included video	.99
Post included photo	.70
Personal self-disclosure of identity (Photo)	.70
Personal self-disclosure about diabetes	.68
Mention of term "self-management"	.99
Referral to other resources	.62
Ask a question	.71
Post made by engagement leader	.83
Information about diabetes cure	.99
Mean	.82
SD	.15

Chi-square analyses were conducted to examine differences between group purpose (information sharing, social support, promotion) and types of media (text, photo, video) referenced in wall posts. A series of multivariable logistic regressions evaluated associations between group activity (active, inactive) and whether (yes/no): questions were asked in posts; referrals were made to other web resources; self-disclosures (eg, display personal photograph, reveal diabetes diagnosis) were made; posts were uploaded by engagement leaders, liked, shared, or commented on. Similar logistic regression analyses examined associations between engagement leader posts (yes/no) with the presence (present/not present) of different types of communication (self-disclosure of identity and diabetes status, referrals to external web resources, and questions) and media (text, video, photo) on wall posts. Odds ratios were computed with 95% confidence intervals ($\alpha < .05$)

Results

Data Reliability

Kappa agreement between coders ranged from 0.61-0.99 ($M = 0.74$, $SD = 0.15$) for the self-management content areas (Table 2), while kappa estimates for wall post characteristics ranged from 0.62-0.99 ($M = 0.82$, $SD = 0.15$). All kappa statistics were at or near the recommended cut-off value of .70.³⁷

Group Characteristics

Thirty-four diabetes Facebook groups met inclusion criteria (Table 3). Most of the groups (20/34, 58.8%) were created with a primary purpose of instrumental support, and 35.3% (12/34) were primarily intended for reciprocal emotional support. Only two groups (5.9%) had a promotional purpose to highlight a diabetes-related product or service, while none were operated by a nonprofit organization for fund raising purposes. Most (26/34, 76.5%) did not specify a focus on Type 1 and/or Type 2 diabetes. The median duration of group existence was 48 (IQR = 51) months or about four years. The two promotional groups were in existence for the largest amount of time (Mdn = 102 months). The total amount of time groups became public on Facebook was inversely related to the number of members gained over the last 30 days (Spearman's $\rho = -0.541$, $P = .001$).

Group Administrators/Moderators

On average, there were about two administrators assigned to each group (Mdn = 2, IQR = 2-3.25), with virtually no moderators in place (Mdn = 0, IQR = 0-0.25). While all groups had at least one administrator, 26 of the 34 (76.5%) largest groups did not list any moderators of group activity. The number of group moderators was positively correlated with the number of group members gained in the past 30 days (Spearman's $\rho = 0.619$, $P < .0001$). Almost half of the groups (16/34, 47%) did not specify a country of origin. Among the administrators for whom country was known ($n = 18$), seven originated in the United States, five were from India, three from the United Kingdom, and the remainder ($n = 3$) started in other countries. The majority of posts ($n = 185$, 58%) were uploaded by an engagement leader.

Group Size

We identified 193 458 Facebook users who were members of the 34 largest diabetes Facebook groups. Groups ranged widely in size from 804 to 22 117 members per group. The median number of group members across all groups was 3123.5 members (IQR = 1297.5-8522.75 members), with the largest number of members belonging to information sharing (Mdn = 4677.5). The largest diabetes-related Facebook group (Diabetes Support) originated in the United States and had been in operation for only 12 months. The smallest group (Sandy Lake Health and Diabetes Activities and News) originated in Canada approximately five years ago. The median number of new group members in the past 30 days was 41.5 (IQR = 5.75-189.25) members, with growth highest within information sharing (Mdn = 60) groups. The total number of members per group was positively associated with the number of group members gained over the past 30 days (Spearman's $\rho = 0.492$, $P = .003$).

Table 3. General Characteristics of 34 Largest Public Diabetes Facebook Groups as of October 2018.

Group name	Number of members	Number of new members in past 30 days	Type of diabetes in focus	Number of posts in past 30 days	Months in operation	Country of origin	Engagement leader present ^a
Diabetes support	22 117	701	N/S	831	12	USA	No
Diabetes recipes	20760	43	N/S	1	72	Unknown	No
Diabetes cure without medicine	18076	450	N/S	54	36	India	Yes
Diabetes support group	16501	186	N/S	241	36	India	Yes
Diabetes awareness	13985	30	N/S	2	60	Unknown	Yes
Awareness centre on diabetes and heart diseases (SVCCZ)	11 552	72	N/S	6	48	London	Yes
Living with diabetes	11 228	527	Type 2	170	7	Unknown	Yes
The freedom from diabetes group	10706	199	N/S	50	48	India	Yes
International friends with type 1 diabetes	7795	40	Type 1	7	84	Unknown	Yes
DOWN WITH CARBS #1- LOW CARB/DIABETIC FRIENDLY RECIPES	5872	398	N/S	797	24	Unknown	Yes
Diabetes society of Maldives	5655	10	N/S	4	120	Maldives	Yes
Juvenile diabetes type 1 support group	5424	54	Type 1	129	24	USA	No
CardioDiabetes secrets	4699	782	N/S	378	36	Egypt	Yes
Diabetes support group	4656	16	N/S	39	36	USA	Yes
Radical roads, diabetes the silent killer	3464	3	N/S	6	132	Unknown	Yes
Diabetic diets	3304	25	N/S	0	24	USA	Yes
Indian diabetics	3288	60	N/S	80	108	India	No
I have type 1 diabetes	2959	3	Type 1	25	144	Unknown	No
The non-corrupt diabetes association	2479	8	N/S	23	48	Unknown	Yes
Mary's diabetic and lowfat recipes	2463	0	N/S	1	48	Unknown	Yes
Diabetes support cancer/hypertension/diabetic group	1430	431	N/S	44	4	India	Yes
Type 2 diabetic recipes and food hints	1405	95	N/S	544	12	Unknown	Yes
Malta diabetes association	1357	260	Type 2	80	72	Unknown	No
Diabetes self-management tips	1326	29	N/S	18	84	Malta	Yes
Diabetes self-management tips	1319	0	N/S	3	12	Unknown	Yes
HOME COOKED HEALTHY RECIPE EXCHANGE AND SOME DIABETIC RECIPES	1299	6	N/S	1	72	USA	Yes
Diabetic friendly & low-fat recipes	1293	8	N/S	8	48	Unknown	Yes
Lions fight diabetes	1245	135	N/S	86	36	Unknown	Yes
Diabetes awareness & You (Day)	1155	2	N/S	16	84	Unknown	Yes
Life through the eyes of a type 1 diabetic awaiting a kidney/pancreas transplant	1090	77	N/S	38	12	UK	Yes
Death to diabetes	1059	5	Type 2	3	96	Unknown	Yes
Reality 4 diabetes	851	2	N/S	3	72	USA	Yes
Diabetic type 2 recipes and support	842	66	Type 2	220	24	USA	Yes
Sandy Lake health and diabetes activities and news	804	3	N/S	15	72	Canada	Yes

^aPresence of group engagement leaders identified following review of 20 most recent Group wall posts. N/S = Not Specified.

Wall Post Content and Characteristics

The median number of group wall posts during the past 30 days was 24 posts (IQR = 3.75-96.75) (Table 4). Many wall posts provided instrumental support (n = 219, 68.7%), with far fewer providing emotional support (n = 80, 25.1%) or promoting diabetes-related products or services (n = 20, 6.3%). Less than 5% of wall posts (n = 14) promoted alternative cures for diabetes. Of the five self-management education topics evaluated, the only topic addressed in more

than 30% of posts (n = 107) was nutrition. Medication management (n = 42, 13.2%), blood glucose screening (n = 28, 8.8%), and physical activity (n = 11, 3.4%) received less attention.

Group Wall Engagement

Nineteen of the 34 (55.9%) largest diabetes Facebook groups were inactive or included <50 posts over the past month.

Table 4. Membership Characteristics of 34 Largest Public Diabetes Facebook Groups According to Group Purpose.

Group purpose	Median number of administrators per group (IQR)	Median number of moderators per group (IQR)	Median number of members per group (IQR)	Median member growth in past 30 days (IQR)	Median number of posts in past 30 days (IQR)	Median months in operation (IQR)
Information sharing (n = 20)	2.5 (1.75)	0 (1)	4677.50 (9728.50)	41.5 (236.25)	12 (77.75)	48 (45)
Social support (n = 12)	2 (3.25)	0 (0)	1378 (3679)	60 (169)	41 (178)	30 (54)
Promotional (n = 2)	2 (2)	0 (0)	2157.5 (0)	2.5 (0)	4.5 (0)	102 (0)

While 252 reviewed posts (79%) were “liked,” 114 (35.7%) were shared, and 136 (42.6%) received at least one comment, there was extremely low overall member engagement on wall posts. The median number of “likes” (Mdn = 3, IQR = 1-10) was very low, and, on average, posts were not “shared” (Mdn = 0, IQR = 0-1) or “commented” (Mdn = 0, IQR = 0-2) on by any group members.

Differences in Characteristics of Active Versus Inactive Groups

A Mann-Whitney *U* test indicated that the number of group members gained in the last 30 days was far greater for active diabetes Facebook groups (Mdn = 26.93) as compared to inactive groups (Mdn = 10.05), *U* = 1.0, *P* < .001, η^2 = 73%. The number of group moderators was greater in active diabetes Facebook groups (Mdn = 21.63) compared to inactive groups (Mdn = 14.24), *U* = 80.5, *P* = .004, η^2 = 25.5%, and the number of months since groups started was much longer for inactive groups (Mdn = 23.21) as compared to active groups (Mdn = 10.27), *U* = 34, *P* < .001, η^2 = 43.5%. Level of group wall activity was not significantly associated with number of group members or number of administrators.

Wall Post Communication and Engagement Strategies

Almost all wall posts included text (n = 317, 99.4%) and the majority included photos (n = 192, 60.2%). Very few patients, providers, or informal caregivers were depicted in wall post photos, with only 13.5% (n = 43) of photos depicting people from at least one of these stakeholder groups. A little more than 10% of posts included videos (n = 34), but there were no GIFs posted. Information sharing posts were more likely to include a photo (43.3%), as compared to emotional support (11.3%) and promotion (5.6%) posts, $\chi^2(df = 2) = 15.85, P < .001$ (Table 5). Videos were only included in 34 posts (10.7%). Posts categorized as “information sharing” were less likely to include a video, as compared to social support and promotional posts, $\chi^2(df = 2) = 9.21, P = .01$. Questions about diabetes appeared in only about 20% (n = 67) of wall posts. However, 67.4% of wall posts (n = 215) directed group members to external online resources (ie, website, other Facebook page, other Facebook group) for

Table 5. Frequency of Media Modes Included Within Wall Posts (n = 319) of 34 Largest Public Diabetes Facebook Groups Categorized by Group Purpose.

Wall post media mode	Group purpose		
	Information sharing, n (%)	Social support, n (%)	Promotion, n (%)
Text included			
Yes (n = 317)	217 (68.0)	80 (25.1)	20 (6.3)
No (n = 2)	2 (0.6)	0 (0.0)	0 (0.0)
Photo included			
Yes (n = 192)	138 (43.3)*	36 (11.3)	18 (5.6)
No (n = 127)	81 (25.4)	44 (13.8)	2 (0.6)
Video included			
Yes (n = 34)	31 (9.7)**	3 (0.9)	0 (0.0)
No (n = 285)	188 (58.9)	77 (24.1)	20 (6.3)

P* < .05. *P* < .001.

additional information related to wall post content. Only 10% of reviewed wall posts (n = 32) contained self-disclosed personal experiences living with diabetes.

Most posts made by engagement leaders did not self-disclose personal information (n = 177, 95.7%) or ask questions (n = 159, 79%). Table 7 shows that posts made by regular group members were almost 5 times more likely than posts by engagement leaders to include a self-disclosure (Wald = 13.66, *df* = 1, 95% CI: 2.09-11.12, *P* < .001, Nagelkerke *R*² = 10.2%). Similar to self-disclosures, posts made by regular group members were nearly three times more likely to pose a question than posts made by engagement leaders (Wald = 12.31, *df* = 1, 95% CI: 1.55-4.69, *P* < .001, Nagelkerke *R*² = 6.1%). Conversely, posts uploaded by engagement leaders were more than two and a half times more likely to refer group members to external web-based resources as compared to posts made by regular members (Wald = 15.20, *df* = 1, 95% CI: 1.55-4.69, *P* < .001, Nagelkerke *R*² = 6.6%).

Communication Strategies Used in Public Diabetes Facebook Groups

Table 6 describes results from multivariable logistic regression analyses, which showed that posts with referrals were 3.33 times more likely to be made in active versus nonactive

Table 6. Associations Between Member Posts and Communication Strategies/Media Used in Public Diabetes Facebook Group Wall Posts (n = 319).

Characteristics of wall posts	Post by engagement leaders, n (%)	Post by regular group members, n (%)	OR (95% CI)	P value
Self-disclosures				
Present	8 (2.5)	24 (7.5)	4.83 (2.09, 11.12)	.0001**
Not present ^a	177 (55.5)	110 (34.5)		
Referrals				
Present	141 (44.2)	74 (23.2)	2.60 (1.61, 4.20)	.0001**
Not present ^a	44 (13.8)	60 (18.8)		
Question(s)				
Present	26 (8.2)	41 (12.9)	2.70 (1.55, 4.69)	.0001**
Not present ^a	159 (49.8)	93 (29.2)		
Text included				
Present	184 (57.7)	133 (41.7)	0.723 (0.045, 11.66)	.936
Not present ^a	1 (.3)	1 (.3)		
Video included				
Present	25 (7.8)	9 (2.8)	0.461 (0.21, 1.02)	.057
Not present ^a	160 (50.2)	125 (39.2)		
Photo included				
Present	119 (37.3)	73 (22.9)	0.664 (0.422, 1.045)	.077
Not present ^a	66 (20.7)	61 (19.1)		

^aReference value used in binary logistic regression analysis.

***P* < .001.

Table 7. Associations Between Group Activity Level and Characteristics of Public Diabetes Facebook Group Wall Posts (n = 319).

Characteristics of wall posts	Nonactive group, n (%)	Active group, n (%)	OR (95% CI)	P value
Self-disclosure				
Included	2 (0.6)	10 (3.1)	0.45 (0.09, 2.22)	.32
Not included ^a	39 (12.2)	88 (27.6)		
Referral				
Included	33 (10.3)	54 (16.9)	3.33 (1.41, 7.69)	.006*
Not included ^a	8 (2.5)	44 (13.8)		
Question(s) asked				
Yes	11 (3.4)	23 (7.2)	1.19 (0.52, 2.78)	.675
No ^a	30 (9.4)	75 (23.5)		
Post by engagement leader				
Yes	33 (10.3)	45 (14.1)	4.86 (2.04, 11.63)	.0001**
No ^a	8 (2.5)	53 (16.6)		
Post liked				
Yes	37 (11.6)	88 (27.6)	1.05 (0.280, 3.227)	.936
No ^a	4 (1.3)	10 (3.1)		
Post shared				
Yes	20 (6.3)	41 (12.9)	1.32 (0.64, 2.78)	.452
No ^a	21 (6.6)	57 (17.9)		
Post commented on				
Yes	26 (8.2)	38 (11.9)	2.74 (1.29, 5.81)	.009*
No ^a	15 (4.7)	60 (18.8)		

^aReference value used in binary logistic regression analysis.

P* < .01. *P* < .001.

groups (Wald = 7.48, $df = 1$, 95% CI: 1.41-7.69, $P = .006$, Nagelkerke $R^2 = 8.1\%$), while posts with comments were 2.74 times more likely to appear in wall posts of nonactive groups (Wald = 6.84, $df = 1$, 95% CI: 1.29-5.81, $P = .009$, Nagelkerke $R^2 = 6.7\%$). Posts made by engagement leaders were 4.86 times more likely to appear in inactive rather than active groups (Wald = 12.72, $df = 1$, 95% CI: 2.04-11.63, $P < .001$, Nagelkerke $R^2 = 13.7\%$). Group activity level was not significantly associated with self-disclosures, questions, likes, or shares.

Discussion

Comparison With Prior Works

The current study represents a critical look at the activity of the largest public diabetes Facebook groups, especially in relation to the communication and engagement activities presently occurring on group walls. Information sharing and awareness creation is common within publicly available Facebook groups related to chronic disease.^{38,39} However, contrary to findings reported in Greene et al, only 10% of wall posts in our study highlighted personal members' experiences living with diabetes. Most wall posts, instead, directed group members to other online resources (eg, website, other Facebook page, other Facebook group) for additional information. Likewise, group members shared informational content with fellow group members instead of reflecting on their own personal experiences. This finding is not surprising as individuals with diabetes remain concerned about how online health portals work and what the rules are for sharing personal health information.⁸ Moreover, results suggest that public diabetes Facebook groups are being used more to supplement and/or obtain knowledge about diabetes, rather than supplement or replace offline social support.

Greene and colleagues²⁵ reported almost 30% of posts promoted a specific diabetes-related product or service (eg, testimonials advertising non-FDA-approved "natural" products). This study, however, reported only about 6% of promotional posts, with less than 5% marketing complementary and alternative medicinal cures. Rather than being a platform solely for emotional support and advertisements, public diabetes Facebook groups are being used more as a "home base" for individuals to access supplementary self-management resources from others. It is important to note that newer social media platforms (eg, Twitter, Instagram, YouTube, Pinterest) are increasingly becoming used for health-related purposes by many engaged patients and advocates.^{27,40,41} Future social network analyses should explore actual use of these popular and emerging social media platforms among patients with diabetes.

Group Membership and Wall Post Characteristics

There were about 3000 members per group. The group with the largest membership focused on information sharing,

rather than emotional support. The vast majority of individuals with diabetes use Facebook to find health-related information on social media.⁷ On average, the number of members per public diabetes group in this study was far larger than membership numbers reported in more specialized diabetes groups focused on foot care (Mdn = 265.7 members, IQR = 3.5-107.75 members).²⁴ This indicates that people with diabetes may be more likely to become members of diabetes groups that discuss broad topics related to the condition.

Despite the popularity of generic diabetes groups, the only diabetes self-management topic addressed in more than 30% of posts was nutrition. It may be that group members are more likely to share nutrition information because activities such as recipe sharing build a greater sense of community. Future studies of both public and private diabetes Facebook groups should investigate the dietary accuracy and perceived usefulness of such nutrition posts. Topics including medication management, blood glucose screening, and physical activity were rarely addressed, perhaps because exercise and taking medications are less enjoyable disease management issues to discuss.

Group Communication and Engagement via Wall Posts

Within inactive Facebook groups, the majority of wall posts were uploaded by an "engagement leader." Engagement leader posts rarely disclosed personal information or posed thought-provoking questions to fellow group members; rather, their posts were more likely to refer group members to external web resources. Facebook groups can sometimes be taken over by a few unprincipled, yet engaged, members who may be prolific posters, but who sometimes bother other members to the point that members become less active, a phenomenon which could contribute to groups being designated as "active" versus "inactive." Regular members, on the other hand, were far more likely to post self-disclosures and post questions. Further research is required to understand how "regular" members of Facebook groups perceive "engagement leaders," particularly regarding the extent to which disconnects in reciprocating self-disclosures affect the group experience (eg, accessing desired information/support).

The total number of members per group was not associated with user engagement, or level of Facebook posting activity. This indicates that having more group members does not necessarily lead to greater group engagement. Usefulness of Facebook groups is not generally associated with number of likes or presence of user comments.²⁴ There exists potential for Facebook groups to offer indirect support (ie, greater perceived social support from greater number of friends) and passive engagement benefits (ie, gathering of new information by social media "lurkers") that cannot be captured by common Facebook analytics.²³ Examining factors that contribute to the perceived credibility of engagement leaders, who frequently post information on Facebook

groups, is important for disseminating relevant, timely, and high-quality diabetes self-management content.

Limitations

This study was not free of limitations. First, this study used limited search terms and was cross-sectional in nature. Like Greene and colleagues,²⁵ we may have missed more longitudinal or seasonal aspects of communication about diabetes. We also only evaluated public groups operated or able to be translated into the English language. Private (“closed”) Facebook groups, in which Facebook users cannot see posts without first requesting an invitation or being invited to join by a peer administrator, were excluded from the search for ethical reasons. It is possible that the increased privacy of these groups may lead to different types of group wall posts or activities. In this study, we used predefined directed codes central to diabetes education, rather than a qualitative approach to inductively identify codes. This limited our ability to identify the broad range of topics discussed on the platform, beyond diabetes. Likewise, we were unable to code the quality of wall posts due to these variables being beyond the scope of this exploratory study. This type of assessment would require coders with sufficient clinical experience, which was not possible given personnel constraints.

Practical Implications

There is a relatively large number of Facebook users who belong to public diabetes Facebook groups. These groups provide informational support but exhibit limited engagement. Despite their informational focus, limited attention was afforded to relevant diabetes self-management topics (eg, medication management, physical activity, glucose monitoring). Similarly, not all members of Facebook groups shared their personal experiences about living with diabetes. There is clear potential for leveraging Facebook group technology to improve diabetes self-management support; however, group moderators and health/diabetes educators should collaborate on strategies to optimize information dissemination through more innovative communicative strategies, including the benefits and hindrances of self-disclosures.

Interestingly, there was a negative relationship between amount of group membership and user engagement. Also, it is unclear how lack of membership growth in longstanding groups may affect engagement in diabetes self-management groups. This represents an area of research that requires future inquiry. This is either an indication of group decay or a niche group of users with particular social norms and interests. Health and diabetes educators should use caution when recommending patients with high engagement needs to Facebook groups simply because of their popularity, or number of group members. Although time since initiation and large group membership may be an indication of credibility and established community, the limited activity and

engagement groups may not satisfy the informational and communicative needs of these patients. Future research is needed to understand how lack of engagement and membership growth may affect overall diabetes self-management support shared within groups.

Only 8 diabetes-related Facebook groups designated moderators for group activity, despite a positive association observed between number of moderators and incidence of new group members joining group in the past 30 days. Similar to prior analyses of Facebook groups related to chronic disease,²⁰ very little information was provided on nation of group origin. When this information was included, it was revealed that most groups originated in the United States and India. India remains the country with the highest prevalence of diabetes, mainly due to rapid economic development and urbanization, with some urban areas of India reaching 20% of people living with diabetes.^{42,43} More online social networks might benefit from assigning culturally sensitive moderators with specific expertise to engage international members from minority populations and those living in remote rural areas.⁷

Conclusion

Facebook group participation has been associated with improved knowledge, skills, confidence, and notably improved patient self-management in the context of diabetes.⁴⁴ To date, however, there is a lack of robust evidence describing the advantages and disadvantages of using chronic disease support groups on Facebook.²³ Trends toward patient-centered diabetes management with expertise from multiple health care professionals holds promise in reaching glycemic targets and improving patients’ quality of life.²⁶ As suggested by others,²⁴ results from this study confirm that public Facebook groups show strong potential to deliver inexpensive and authentic self-management knowledge to patients with diabetes.

Abbreviations

GIF, graphics interchange format; IQR, interquartile range; N/S, not specified; SES, socioeconomic status; WHO, World Health Organization.

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