A Comparison of Type 1 and Type 2 Diabetes Online Communities

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Abstract

As more individuals are diagnosed with Type 1 and Type 2 diabetes, efforts to manage the disease have shifted toward online support communities. This paper compared how Type 1 and Type 2 diabetics used Twitter for peer support and disease self-management purposes. Tweets were categorized using quantitative content analysis in an effort to compare emotional and informational support conversations. This analysis revealed that Type 1 diabetics more likely prioritize emotional support activities than Type 2, especially in the area of discussions of giving and personal experience. Type 2 diabetics, however, prioritize informational support activities, such as diet/exercise, research, and lifestyle management. Recognizing these differences would allow for improved individualized treatment for the diabetes epidemic.

I. Introduction

An increase in diabetes diagnoses around the world has triggered concern for the widespread epidemic in recent years. The World Health Organization predicts that the number of diabetes patients will more than double from 171 million in 2000 to 366 million in 2030. As more and more children and adults are diagnosed with Type 1 and Type 2 diabetes, efforts to manage the disease have broadened. The risks of diabetes can be severe and even life-threatening if not properly treated. However, due to the uptick in diabetes patients, healthcare resources are strained when it comes to counseling and individualized treatment options (Brownson & Heisler, 2009).

As social media becomes more popular, chronic disease patients turn to social networking platforms for healthcare advice and support (Hilliard, Sparling, Hitchcock, & Hood, 2015). A recent study by the Pew Research Center found that 34% of caregivers and 20% of patients engage in online healthcare discussion. Even further, 11% of caregivers and 6% of patients actively post experiences or ask questions on social networking sites (SNS) (Sarker et al., 2015). These networks, called diabetes online communities (DOCs), allow patients and caregivers the opportunity to learn more about their disease at no cost, without ever leaving their homes (Hilliard et al., 2015). This is especially important for diabetics in rural areas or patients/caregivers that lack access to healthcare.

The role of emotional and informational support is vital to the chronic treatment of any disease. While emotional support provides patients and caregivers with encouragement and mental guidance, informational

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support supplies the health literacy necessary for proper lifestyle maintenance. The vast network of support on social media allows diabetes patients and caregivers the opportunity to take control of their treatment strategies in an individualized way.

Understanding the motivations and usage patterns within DOCs provides greater insight into the treatment plans needed to manage diabetes. Of course, disease management differs between Type 1 and Type 2 diabetes. The differences between these communities help people better understand the needs of individual patients. Studying the difference between DOCs for Type 1 and Type 2 can also provide healthcare professional guidance when they advise patients/caregivers.

II. Literature Review

The following is a review articles on diabetes self-management, peer support, and online support.

Diabetes Self-Management & Online Informational Support

As resources for diabetics decrease, the importance of health literacy and information grows. As a result of the lack of resources, 20% of diabetics in the United States have poor glycemic control, one-third have poor blood pressure control, and 40% have poor cholesterol control (Brownson & Heisler, 2009). The need for attainable and free healthcare information for diabetes self-management is clear. Defined by the Institute of Medicine, self-management is "the systematic provision of education and supportive interventions to increase patients' skills and confidence in managing their health problems" (p. 7). The self-management theory suggests that knowledge about diabetes is the basis for successful treatment and provides health literacy in areas, such as insulin monitoring skills, understanding the role of carbohydrates in blood glucose control, and the consequences of diabetes (Ho, O'Connor, & Mulvaney, 2014).

The foundation of diabetes self-management is informational support. Rather than relying on social networks for emotional guidance, diabetes self-management allows users to view peers' experiences, treatment options, and outcomes through information sharing. DOCs thus provide an environment for group education where like-minded individuals can discuss self-management behaviors (Willis, 2014).

Diabetes Peer Support

In addition to self-management, peer support is popular among diabetics of both types. As support resources provided by healthcare professionals are sometimes inadequate regarding patient self-care, patients may turn to each other for support (Brownson & Heisler, 2009). Peer support is defined as "the provision of emotional, appraisal, and informational assistance by a created social network member who possesses experiential knowledge of a specific behavior or stressor and similar characteristics as the target population" (p. 8). Unlike self-management, peer support relies on emotional guidance as part of proper treatment. Discussing chronic conditions with peers can help patients/caregivers moderate the fear of their disease while finding a sense of belonging to a group (Brownson & Heisler, 2009). In addition to emotional guidance, peer support can provide informational learning in a group setting. Through the peer learning model, patients have experienced increased "medication adherence, self-reported health status, and better chronic disease self-management" (Brownson & Heisler, 2009, p. 9).

Peer support is an effective means of emotional guidance as it narrows the social distance between the experienced diabetic and the novice diabetic. Patients/caregivers are shown to learn better when taught by trained peers with shared experiences (Brownson & Heisler, 2009). Additionally, research has found that social networking has a conclusive effect on the ability to learn and manage chronic disease (Malhotra, Stockdale, & Wellington, 2008). Social media provides users with a 24/7 connection to peer support, as diabetes online communities continue to grow.

Diabetes Online Communities

The use of social media for diabetes networking and information sharing has evolved from static web browsing to dynamic social discussion. First mentioned in the late 1990s in online chat rooms and discussion boards, the phrase "diabetes online community" was used to indicate online forums and content for diabetics

and their families. In the 2000s, DOCs migrated to social media networks. As of September 2014, more than 1,000 active Facebook groups were dedicated to diabetes communication. In addition to social peer support networks, DOCs on Twitter host live weekly forums where users can discuss experiences in real time (Hilliard et al. 2015).

The existence of DOCs provides researchers the unique opportunity to collect and analyze public social media posts tied to diabetes. The inherent differences between the Type 1 and Type 2 diabetes communities provide an interesting subject of study. Understanding how differently the two DOCs use emotional tone and informational content can provide further insight into the needs of each community. When these needs are identified, healthcare providers can suggest specialized peer support/self-management strategies according to diabetes type.

Understanding the physical differences between Type 1 and Type 2 diabetics is necessary to study the needs of each online community. Type 1 diabetics experience a lack of insulin contributing to hyperglycemia, where onset is most common during youth (Scobie & Samaras, 2009). Type 2 diabetics experience insulin resistance where onset is accelerated by factors, such as obesity and sedentary lifestyle (Scobie & Samaras, 2009). These differences can affect the motivations and behaviors of online use.

Literature suggests that while peer support is critical for both diabetic types, Type 2 diabetics may respond more to self-management tactics, such as weight and lifestyle management. Because nearly 80% of people with Type 2 diabetes are overweight or obese, bodily self-management is vital to the survival of Type 2 diabetics (Mertig, 2012). Alternatively, Type 1 diabetics at a young age require the advice and guidance of their peers regarding insulin products, insulin monitoring, and lifelong treatment. This is especially true due to the onset of Type 1 diabetes during youth (Scobie & Samaras, 2009). Youth Type 1 patients/caregivers will have different diabetes management needs than an adult experiencing Type 2 diabetes due to environmental factors. Ho, O'Connor, and Mulvaney (2014) found that for Type 1 diabetes youth, the most notable features used in DOCs were social learning and networking, which can be tied to peer support. Thus, it is clear that the motivations and behaviors of Type 1 and Type 2 diabetics vary online. Given these differences, it is important to study the emotional and informational content used by diabetics online. The content and emotional themes between the DOCs provide clues into their distinct treatment strategies.

Based on the literature review, the following two research questions were asked:

RQ1. How do diabetes patients/caregivers engage in online communities for the purpose of self-management and peer support?

RQ2. How do Type 1 and Type 2 diabetes online communities differ from each other with regard to the emotional and informational content used in the online discussion?

III. Methods

This research used quantitative content analysis to examine the discussion of diabetes in online communities. In an effort to compare the discussion between Type 1 diabetes and Type 2 diabetes online communities, the author collected social media posts via Twitter with the TwitteR package, one of the packages for the programming language R.

Sampling of Tweets

Nine hashtags that were chosen based on their popularity of use in DOCs were used to download tweets to a CSV file. The three hashtags of #diabetes, #diabeticlife, and #doc yielded general information about diabetes patients and caregivers. The six hashtags of #t1d, #t2d, #type1, #type2, #type1diabetes, and #type2diabetes generated specific information about patient and caregivers for a particular type of diabetes.

Tweets were collected during a seven-week time period beginning August 17, 2017, and ending September 27, 2017. Tweets were collected once a week, alternating weekdays (collection for the first week occurred on a Monday, collection for the second week occurred on a Tuesday, so on and so forth). A seven-week time period was chosen in an effort to develop a constructed week.

Once collected, tweets were separated into two different CSV files by diabetes type. Tweets concerning diabetes in general or discussion of both types were discarded. Only original tweets were kept for analyses after deleting retweets. Of the resulting 13,376 tweets, 11,213 discussed Type 1 diabetes, and 2,163 discussed Type 2 diabetes. For each DOC, 2,000 tweets were randomly chosen for analysis, which generated a total of 4,000 tweets.

Coding Scheme

The author developed categories to compare the content of tweets between the DOCs. A researcher first reviewed all the tweets to determine any emerging themes for both Type 1 and Type 2 diabetes. The author coded a sample containing 10% of all tweets with another coder to establish inter-coder reliability for all categories. The rest of the coding was finished after establishing the inter-coder reliability of .8 or higher. The following are the specific coding categories and subcategories (refer to *Figure 1*.)

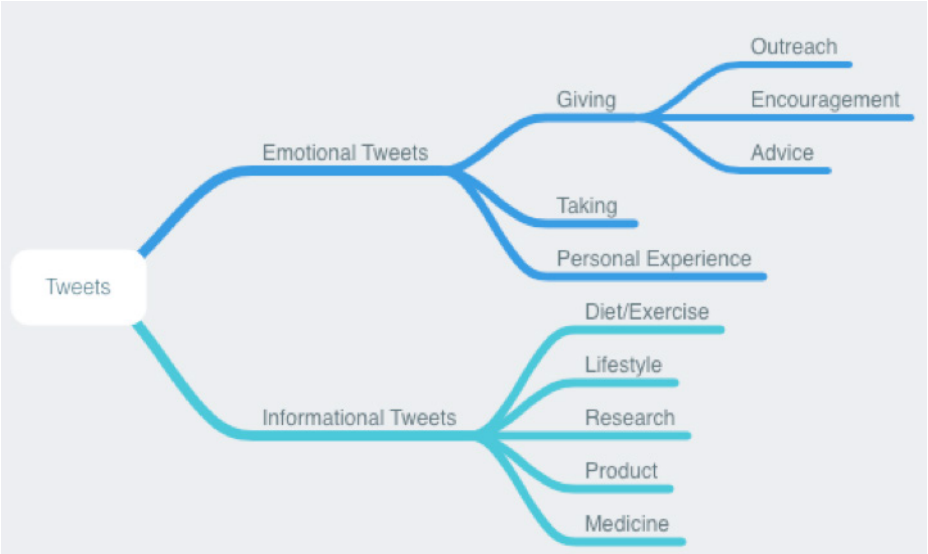

Figure 1. Different kinds of tweets for diabetes patients and caregivers

Emotional vs. Informational Tweets: A tweet with an emotional focus can be defined as one giving or receiving support while expressing joy, sorrow, hate, encouragement, and other feelings or stating a personal experience using an emotional tone. If coded as emotional, a tweet was marked with a 1. Otherwise, it receives a 0.

A tweet with an informational focus is defined as giving or receiving support through educational information or providing/seeking informational resources regarding self-management of diabetes. If coded as informational, a tweet receives a 1. Otherwise, it receives a 0. It should be noted that the emotion and information categories are not mutually exclusive. Instances of emotionally charged tweets with informational suggestions were coded as both emotional and informational, with a 1 given to both categories.

Emotional Tweets: Tweets in these further subcategories were mutually exclusive. Once a tweet was found to be outreach, encouragement, or advice, it was coded as 1 while the others were coded as a 0.

- *Giving* is defined as providing other users with emotional support, such as imparting wisdom or comfort to users in the form of spiritual, psychological, familial, or mental aid.
- *Taking* is defined as asking other users for emotional support. Seeking the wisdom or comfort of other users in the form of spiritual, psychological, familial, or mental aid.
- *Personal experience* is defined as a statement of an event with emotional themes.

Tweets in these three subcategories above were mutually exclusive. Once a tweet was found to focus on giving, or taking, or personal experience, it was coded as 1 and while the others were coded as 0.

- *Outreach* is defined as providing other users with emotional support by discussing community initiatives, support resources, or physical/virtual support.
- *Encouragement* is defined as providing other users with uplifting emotional support, including comfort and optimism to discouraged users.
- *Advice* is defined as providing other users with emotional support via personal recommendations and guidance.

Informational Tweets: A tweet receives a 1 for each of the five subcategories when mentioning the relevant information. Otherwise, it receives a 0 for any of the subcategories.

- **Diet/exercise** is defined as one regarding the diet and exercise of a diabetes patient or caregiver. Recipes, weight loss, fitness programs, food products, etc.
- *Lifestyle* is defined as one regarding the habits and behavior of a diabetes patient or caregiver.
- *Research* is defined as one regarding current research in the diabetes healthcare field.
- *Products* are defined as one regarding diabetes management products such as insulin pumps, monitors, and meters.
- *Medicine* is defined as one regarding diabetes management via pharmaceutical means such as insulin. Tweets in these subcategories were not mutually exclusive as informational content was prone to overlap.

IV. Results

RQ1 asked how diabetes patients/caregivers engage in online communities for the purpose of self-management or peer support. Reviewing the content of the chosen tweets helps us better understand how DOC users engage in self-management and peer support activities online. The emotional status and content of the tweets provide us with more information about diabetes patients and caregivers. Analysis of the frequencies of informational and emotional contents in Type 1 and Type 2 communities helps answer RQ2.

Once the 4,000 tweets were coded using the above coding schemes, statistical analysis was conducted. Using the programming language R, Chi-square tests were run on data in Table 1 to test whether the two variables of diabetes types and content types are totally independent of each other. The Chi-square value with the degree of freedom, 1, was X2(1).=715.67, and its corresponding p-value was less than .01. This means that the Type 1 community and Type 2 community are more likely to issue informational messages than emotional messages, but its tendency is more so with Type 2 than Type 1.

Table 1. Contingency Table of Coding Categories

Category	Type 1	Type 2
Emotional	956 (46.1%)	181 (8.8%)
Informational	1,117 (53.9%)	1,869 (91.2%)

Notes. The number of tweets in total is more than 4,000 because some tweets were coded both as being emotional and informational.

Giving, Taking, Personal Experience Tweets under the Emotional category

The child categories of *giving*, *taking*, and *personal experience* help us understand the type of emotional content being used by DOC patients and caregivers. We can see if users are more likely to impart wisdom, ask for help, or discuss their own experiences via Twitter.

As shown in Table 2, personal experience accounted for the largest portion (23.6%), followed by giving and talking. Its order for Type 2 was different, with giving at the top, followed by personal experience and talking.

The child category of giving further highlights peer support activities of DOCs on Twitter. The emotional conversations of *giving* can be separated into the content of *outreach*, *encouragement*, and *advice*. Overall, content of outreach was used most commonly in both communities as shown in Table 2, 17.3% and 6.7% for Type 1 and Type 2, respectively.

Table 2. Differences between Type 1 and Type 2 in Their Use of Tweets

Community Types	**Community Types**		**Percent Type 2 Diabetes**	
Tweet Types	No. of Tweets	Percentage	No. of Tweets	Percentage
Emotional	956	46.1%	181	8.8%
Giving	450	21.7%	139	6.8%
Outreach	358	17.3%	137	6.7%
Encouragement	60	2.9%	2	0.1%
Advice	34	1.6%	0	0.0%
Taking	29	1.4%	2	0.1%
Personal Experience	471	22.7%	41	2.0%
Informational	1,117	53.9%	1,869	91.2%
Diet / Exercise	146	7.0%	458	22.3%
Lifestyle	408	19.7%	810	39.5%
Research	292	14.1%	542	26.4%
Product	172	8.3%	12	0.6%
Medicine	92	4.4%	48	2.3%
Total	2,073	100.0%	2,050	100%

Diet/Exercise, Lifestyle, Research, Product, Medicine Tweets under the Informational category

While it is clear that the Type 2 DOC is more likely to engage in self-management behaviors through informational content on Twitter, it is important to understand what kinds of content is popular among patients and caregivers.

The most common categories of content for both communities were *lifestyle* and *research* as shown in Table 2. The third most popular content was *product* for Type 1, while it was Diet/Exercise for Type 2.

V. Discussion

It is clear that the two DOCs use Twitter uniquely and for different purposes. Understanding these differences provides us with better insight into the content that is most important for each community. Observing social media post content allows us to see the frequent behavior patterns relating to diabetes

patients' self-management and peer support. As diabetes diagnoses are on the rise, it is important to provide patients/caregivers with targeted management plans. This research offers the evidence of the differences between DOCs, and allows medical practitioners to give targeted advice based on those differences.

Emotional and Informational Tweets

The Type 1 DOC prioritizes emotional content about four times more than the Type 2 community. As supported by the Twitter text, pursuits of peer support are used more frequently in the Type 1 DOC. Generally, instances of peer support require emotional discussion as they are heavy in guidance and advice (Brownson & Heisler, 2009). However, the Type 2 community engages far less in emotional peer support efforts. Their discussion is focused on diabetes prevention, healthcare management, and diabetes awareness.

Informational tweets can be tied to diabetes self-management as their content aligns to the monitoring, control, and research of diabetes for patients and caregivers (Brownson & Heisler, 2009). The majority of tweets from the Type 2 community (91.2%) highlight the importance of managing diabetes as well as steps to prevent the condition. Discussion of recent news and research is also frequent in the Type 2 community.

The parent categories *emotional* and *informational* provide us with a general understanding of DOC usage motivation. While Type 1 patients/caregivers are motivated by peer support online, Type 2 patients/caregivers are motivated by disease management.

Emotional (Giving, Taking, Personal Experience) Tweets

We see the Type 1 community engages in the emotional discussion of *giving*, *taking*, and *personal experience* most often. While Type 1 users frequently provide/give peer support outreach, encouragement, or advice, they are not as likely to ask for guidance or take. While users do not explicitly seek support or guidance through the use of questions, the @reply conversations on Twitter, as well as the "like" and "retweet" features allow for confirmation of post quality. When users are satisfied with the content of a post or when their question is answered, they have the option to amplify a post's popularity rather than asking their own question. These features allow emotional content to be spread more widely instead of repeating questions.

Similarly, Type 1 users are likely to post about personal experiences. This may be due to the general purpose of social media, i.e., updating friends and family through personal posts. In many ways, providing personal experiences is a type of peer support as it encourages empathetic listening (Gilbert, Dodson, & McKenzie, 2012). On Twitter, patients and caregivers can listen to the experiences of like-minded individuals, helping them "cope with social or emotional barriers" to "stay motivated to reach their goals" (Gilbert et al., 2012, p. 180).

Type 1 users are likely to engage in giving and personal experience discussion, which Type 2 users seldom participate. The Type 2 community does not engage in emotional conversation frequently; instead, chose to discuss informational topics. As stated, these topics are tied to self-management activities and diabetes lifestyle discourse.

Giving (Outreach, Encouragement, Advice) Tweets

The emotional discussion of giving is again used more frequently by the Type 1 diabetes community. The actions of *outreach*, *encouragement*, and *advice* are directly linked to peer support as they provide other users with comfort and guidance. Outwardly assisting community members is a strong feature of the Type 1 community. Patients and caregivers feel they have emotional guidance to offer, so they disclose personal psychological information. In addition, instances of awareness outreach are common in the Type 1 community. Users are more likely to invite patients/caregivers to physical peer support groups, awareness campaigns, and diabetes events, furthering the peer support profile.

While the Type 1 community is steeped in emotional giving, the Type 2 community engages less frequently in giving activities. The Type 2 community almost never provides *advice* or *encouragement*, but may sometimes engage in diabetes outreach. Using the Twitter text as support, the most frequent examples of Type 2 outreach are invitations to physical peer support groups. Type 2 individuals would sometimes provide a date, time, and location for upcoming peer support circles. This demonstrates that while the Type 2 DOC is focused on lifestyle self-management techniques, they still value peer support as a form of diabetes management.

Informational (Diet/Exercise, Lifestyle, Research, Product, Medicine) Tweets

Informational content is used frequently in both diabetes communities (53.9% for Type 1 and 91.2% for Type 2), but overwhelmingly in the Type 2 community. As discussed earlier, the Type 1 community is more likely to prioritize emotional discussion and peer support activities than the Type 2 community, which solely focuses on self-management discourse.

Type 2 users tweet most frequently about *diet/exercise*, *lifestyle*, and *research*. These categories align with traditional diabetes self-management tasks as they discuss problem-solving as well as treatment options and outcomes (Willis, 2014). The most popular category used by the Type 2 community is *lifestyle*. With the Twitter text, the Type 2 DOC discusses *lifestyle* in reference to school/work, seasonality, and diabetes news. These discussions can provide readers with context about how to manage their disease in innovative ways.

Diet/exercise and *research* are similarly popular categories for Type 2 patients/caregivers. As the treatment of Type 2 diabetes requires constant weight/diet management for insulin sensitivity, it is understandable that the Type 2 community engages in this discussion frequently (Scobie & Samaras, 2009). We also see the research category employed more regularly in the Type 2 community. Using the Twitter text as support, the Type 2 DOC discusses research in the context of obesity, clinical trials, and treatment options in testing.

The final two informational categories, *products* and *medicine*, are used more by the Type 1 diabetes community. This may be due to the constant monitoring and medical supervision required for Type 1 diabetes (Scobie & Samaras, 2009). The use of insulin pumps, monitors, and test strips is thus more commonly discussed in the Type 1 community. The same is true for the *medicine* category. Type 1 diabetes is treated with insulin to sustain life while insulin treatment is just one management option for Type 2 diabetics (Scobie & Samaras, 2009). Thus, the Type 1 community may be more inclined to discuss medical information on Twitter.

VI. Conclusions

This research demonstrates the value of online communities as methods of peer support and self-management for diabetes treatment. As supported by the Twitter communities, Type 1 diabetics are more likely to prioritize emotional support activities than Type 2, especially discussions of *giving* and *personal experience*. Type 2 diabetics, however, prioritize informational support activities, such as *diet/exercise*, *research*, and *lifestyle* management. Recognizing these differences allows for improved individualized treatment for the diabetes epidemic.

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