Online Social Networking by Patients with Diabetes: A Qualitative Evaluation of Communication with Facebook

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BACKGROUND: Several disease-specific information exchanges now exist on Facebook and other online social networking sites. These new sources of knowledge, support, and engagement have become important for patients living with chronic disease, yet the quality and content of the information provided in these digital arenas are poorly understood.

OBJECTIVE: To qualitatively evaluate the content of communication in Facebook communities dedicated to diabetes.

DESIGN: We identified the 15 largest Facebook groups focused on diabetes management. For each group, we downloaded the 15 most recent "wall posts" and the 15 most recent discussion topics from the 10 largest groups.

PATIENTS: Four hundred eighty unique users were identified in a series of 690 comments from wall posts and discussion topics.

MAIN MEASURES: Posts were abstracted and aggregated into a database. Two investigators evaluated the posts, developed a thematic coding scheme, and applied codes to the data.

KEY RESULTS: Patients with diabetes, family members, and their friends use Facebook to share personal clinical information, to request disease-specific guidance and feedback, and to receive emotional support. Approximately two-thirds of posts included unsolicited sharing of diabetes management strategies, over 13% of posts provided specific feedback to information requested by other users, and almost 29% of posts featured an effort by the poster to provide emotional support to others as members of a community. Approximately 27% of posts featured some type of promotional activity, generally presented as testimonials advertising non-FDA approved, "natural" products. Clinically inaccurate recommendations were infrequent, but were usually associated with promotion of a specific product or service. Thirteen percent of posts contained requests for personal information from Facebook participants.

CONCLUSIONS: Facebook provides a forum for reporting personal experiences, asking questions, and receiving direct feedback for people living with diabetes. However, promotional activity and personal data collection are also common, with no accountability or checks for authenticity.

INTRODUCTION

When gathering information about medical conditions or treatment, patients are increasingly looking to the Internet for data [1]. One recent survey indicates patients search the Internet more frequently than they communicate with their doctors about health care questions [2]. Patients also seek to meet and interact with a community of patients with similar problems, both to share clinical information and to provide and receive support [3–5]. This type of dynamic online communication—called "Health 2.0", in contrast to earlier static health-related websites—now offers patients an opportunity to build and benefit from a social network to learn about their illness and to gain support from others with similar experiences. Outside of the Internet, social networks have been shown to improve disease management and health outcomes for patients [6–8].

With over 400 million registered users worldwide, Facebook is an important online meeting place for social networking [9]. Many sites of disease-specific groups have arisen on Facebook, representing important sources of information, support, and engagement for patients with chronic disease [10,11]. However, relatively little research to date has explored the information that patients request, the unsolicited information that is provided, or the nature of the virtual communities that congregate on Facebook.

Important questions exist about the extent to which private firms promote their products in this unregulated environment. Physicians and patients are unaware of the extent to which information on Facebook is clinically accurate and whether patients receive advice to engage in potentially harmful activities. Accordingly, we evaluated a sample of discussions on the most popular Facebook pages dedicated to diabetes, an important chronic disease that requires intensive treatment

and management, to qualitatively describe the information that Facebook users share.

METHODS

Study Sample and Data Collection

Using the Facebook search function, we searched for the word "diabetes" in the title of Facebook groups. We identified the largest groups on Facebook focused on patients with diabetes or people who know or care for them. On August 8, 2009, we identified the 15 most recent "wall posts" from the 15 largest groups and the 15 most recent discussion topics from the 10 largest groups. The quotes were then aggregated into a database.

"Wall posts" are comments made by group members on a central group webpage and serve as a way to query or communicate with all group members. The more conversational "discussion groups" represent topic-based threads initiated by a single member and continuing to allow other group members to respond to the initial comments and any subsequent comments in the discussion topic. In total, we captured 233 wall post comments and 457 discussion topic comments in our database.

Analysis

Comments were evaluated by at least two researchers (W.H.S, E.K., and J.A.G.). The evaluators read all posts in the sample, and using the method of content analysis, developed descriptive codes based on broad themes in the data [12]. Evaluators read comments from both the wall posts and discussion topics, and developed a unified coding scheme. No new codes arose after approximately 25% of the data was assessed, suggesting near saturation.

Codes were assigned to the data by at least two evaluators independently. There was a high level of agreement, and all discrepancies were discussed by the two evaluators until a consensus was met. Any conflicts were considered and adjudicated by all three evaluators. Individual users were identified by a unique identifier so that multiple occurrences of a sentiment by the same participant were only coded once. Statements were coded as potentially harmful if two clinicians agreed that incorrect clinical information was transmitted that could be harmful to a patient. Codes were entered into an Access database [13] for descriptive analysis.

RESULTS

The 15 largest groups included an average of 9,289 participants (range 1,107–61,957) each. The study sample included 690 individual posts on wall pages and discussion boards written by 480 unique users. While we only abstracted the most recent 15 posts from each discussion topic, the duration of communication in those threads ranged from less than 1 day to over a year and a half (587 days). During the study period, the majority of users [362 (75%)] only placed one post, 44 (9%) posted three or more times, and one user posted 14 times during the study window. Of the users posting 3 or more times, 13 (30%) were clearly promoting products, and 2 (5%) were conducting online surveys, while 29 (66%) represented personally engaged users.

Codes for wall posts and discussion content were assigned to one of five categories [1:] information-providing posts, in which a poster shared his or her own solicited or unsolicited experience and advice [2:] requests for information, in which posters posted general or specific queries to the Facebook community [3:] demonstrations of support, in which posters provided emotional support in response to specific narratives [4:] obvious promotional messages for products and services, and irrelevant posts that had no relation in form or content to the subject or discussion threads [5]. Any given post could contain one or more of these coding categories. Figure 1 shows the relative frequencies of these coding categories as a percent of all posts.

Four prominent themes emerged from the coded data: information-sharing, patient-centered management, community-building, and the marketing and data collection functions of Facebook diabetes groups.

Information-sharing

The majority of posts sampled (66%) described users' personal experiences with diabetes management. Users offered illustrations of how Facebook-specific information supplanted and/or integrated into other forms of diabetes-related information. As one member described to a newer member of a diabetes Facebook group,

> I think the Internet is your best bet. The books I bought ranged from you'll never eat normally again to your life is about to suck big time. I think you should download a diet…get together with a diabetic counselor and try this free website.

The respondent thanked him for this advice, reported that (s)he would use the website, and further suggested the use of another downloadable iPhone application that performed calorie and exercise tracking.
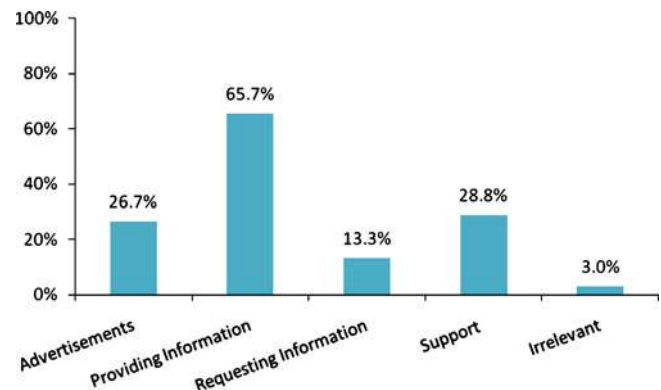

Figure 1. Relative frequencies of coding categories as percentages of total posts coded.

Other posts highlighted the value of Internet-based communication and questioned the guidance provided by health providers and formal patient advocacy organizations such as the American Diabetes Association. These users claimed that the search for a "cure for diabetes" made more headway through Internet communication pathways than through a medical profession content to "merely manage" the condition. Cynical users claimed that many physicians had no incentive to refer patients to potentially 'curative' surgical interventions for obesity, "out of ignorance or out of fear of losing all that money for office visits." Paradoxically, these narratives discrediting physicians as limited sources of information often attempted to validate the use of Facebook as a source of diabetes information.

Adverse event reporting received particular attention as a potentially powerful extension of social networking media. Users posted individual concerns about possible adverse effects of medications and diet supplements in attempts to see if their own experiences correlated with that of others. The following query regarding long-acting insulin glargine therapy drew several responses claiming adverse effects:

> Severe weight gain? Tired? Mood changes? Body aches? Insulin resistance belly fat? I have been seeing a correlation between this drug and all the above. Nothing formal as far as polls, but just asking folks that I believe are diabetic and showing signs of insulin resistance…IS THERE ANYBODY ELSE QUESTIONING THIS??????? Are you involved in the same argument with your medical team as I am? Any feedback would be appreciated! PLEASE.

Several users reaffirmed the observations of the initial post by re-framing their own personal history within the categories of a putative adverse effect of insulin glargine, e.g.:

> Omg you are so right…I have gained about 40 pounds in 2 yrs I've been on lantus. I've had type 1 for 17 yrs im starting the pump this Friday so im hoping it works well for me. I always blamed my sit down job but this weight gain started when I started lantus…

Other users, however, contested the glargine adverse effect hypothesis. One agreed he had also felt "the weight gain, fatigue, MOOD CHANGES and body aches but that may not be the Lantus…maybe the diabetes causes our weight gain (and losses)." Another user suggested that only a low threshold of adverse effects should be tolerated for Lantus as the drug did not represent a fundamental innovation over other long-acting insulins such as NPH, complaining that patients and doctors were deluded into "thinking the Lantus is actually doing something, and it might be, causing cancer."

Patient-centered Management

Nearly one quarter (24%) of posts shared sensitive aspects of diabetes management unlikely to be revealed in doctor-patient interactions. One series of posts described how to count carbohydrates in type I diabetes to enable extended alcoholic drinking sessions without risking ketoacidosis. Another series

discussed the metabolic needs of diabetic triathletes—a highly specialized form of experiential knowledge not available to primary care physicians or even many endocrinologists, but readily available through discussion threads of those diabetic patients who had performed multiple triathlons.

These discussions favored patient-centered goals—as opposed to physician-centered metrics—for diabetes care based on the recognition of limitations, unconditional emotional support, and encouragement of achieving smaller, self-defined goals. This is evident in the following exchange regarding the merits of 'loose' over 'tight' glycemic control:

> …I don't mean to sound negative, because I am just being realistic. After 36 years of living with type 1, the idea of having 'tight control' is a goal that the doctors would like you to constantly aim for. But the reality is that with all of the variables involved, … it is not feasible to maintain 'tight control.' … [W]hen your A1c comes back at 8.3, don't beat yourself up too much. So long as you have done the best that you can then you deserve congratulations and a pat on the back.

> …It is true, keeping tight control seems like an unreachable goal. I have had diabetes for 26+ years and have not seen anything less than a 7.2 A1C. But I keep trying. I always feel like a failure when my A1C comes back. …. I just keep pushing forward and one day…maybe…I will have a good A1C. … Good luck… and remember we are in this together!!! Everyone on these threads have really good information and are very helpful!!!

Patient-centered approaches were not universally "looser" than provider-centered approaches. Several users chastised their providers for not showing enough attention to their sugar measurements and used Facebook discussions to reinforce their own justifications for tight control. These users complained that the once a day dosing of glargine insulin was too easy and advocated blood sugar checks with insulin titrations every 2 h.

Interpersonal Support and Community Formation

Users frequently confronted questions of diabetic identity and the authenticity of an online community of diabetics. Many discussion threads were initiated by posters who claimed to be "new" diabetics, and received replies from "seasoned" diabetics helping to frame their expectations, alternately encouraging them that their lives would be manageable, while warning them to expect the routine difficulties of the diabetic life. Other discussions were initiated by seasoned diabetics and debated what it meant to be, and at what moment one became, a diabetic. As one poster noted, "[I]t is not when you were diagnosed, it is when you first started feeling like S___T that matters for a date you were actually diabetic."

> I was likely about 7 years old when I was actually feeling like S___T. But I was not diagnosed then. Luckily I never had complete failure, just enough so I had lots of vomiting and diarrhea. …So here I am walking around with a pancreas functioning just enough so I could stay alive. The schools thought I was mentally retarded and

after I received insulin I went from being retarded to a genius.

Similar storytelling threads clustered around call-and-response elements such as a group of responses to the query "what was your scariest moment?," which generated narratives of hospitalizations and hypoglycemic comas that blended fear with humor:

> I woke up before anyone else at home because my arm was moving itself and hitting the wall separating mine and my parent's bedroom. I didn't know what was going on and I tried to grab it with my other hand but I just couldn't keep hold of it. When my mum came in and started talking to me I couldn't get any words out…So she grabbed the glucagon and tried to inject me with it and I came to life (I don't remember a thing) and started thrashing around and cackling like a witch at her! …When I saw the ambulance finally come up our driveway, I was convinced I had died and that they were coming to take me away and I started bawling my eyes out.

As stories accumulated in threads they referenced one another and affirmed shared membership within a diabetic community. In the "scariest story" thread above, a respondent layered her own narrative with direct reference to the post cited above:

> Wow…I'm so sad you had to go through that. But you have described it very well. The not being able to control your movements is very scary. I've had that a lot over the years. With the speech, I've had a similar thing. I wrote my flatmate a note, asking him to call my work and tell them I wouldn't be coming in. He showed me the note the next day and it was neat, but there wasn't any English in it. It was as if it was written in another language. Very scary.

More concrete efforts at community-building involved explicit organization of political activism. Users employed Facebook to inquire into insurance coverage issues across geographic regions and insurance plans, and to urge members to write letters to specific insurers and politicians to change coverage decisions. At times this was accomplished through specific Facebook groups formed in partnership with drug or device sales representatives to alter Blue Cross/Blue Shield coverage decisions regarding insulin pumps or continuous glucose monitoring. For example:

> The local Medtronic rep has let us know that BC/BS will be reviewing all comments made to them on this topic soon, so June 13th is the deadline to send a comment. Even if you are not a BC/BS policy holder, please send a comment anyway. …Here's how you can make your thoughts known:…

Facebook as a Marketing Space

While the majority of posts did not promote specific products, advertising was a prominent activity across all diabetes-related discussion threads and wallposts. Explicit product promotion was found in more than a quarter (27%) of all discussion threads and wallposts. The majority of promotional posts promoted dietary supplements and "natural cures" for diabetes. A smaller number of posts advertised diet and exercise counseling services and books for managing diabetes.

While only 3% of all of posts contained inappropriate or unsupported therapeutic claims, 36% of these posts related to advertisements for non-FDA approved products. These promotional materials exclusively took the form of first-person testimonials by 'sharing' personal opinion to propose claims of efficacy and unproven mechanisms of action:

> I wanted to share this information that I have concerning the natural antioxidant known as Alpha Lipoic Acid (ALA) and how it can help you in your fight against diabetes. Alpha Lipoic Acid benefits people with diabetes and heart disease by helping to prevent cell damage throughout the body—a natural antioxidant which attacks free radicals that cause damage to the cells in the body—supplements help to rid the body of harmful substances from the environment. These are reasons why we include Alpha Lipoic Acid in [BRAND NAME PRODUCT]…Talk to you soon, XXX.

Other promotional posts explicitly referenced consumer trust in Facebook-based information over formal avenues of health information to promote their products, for example:

> My brother asked a pharmacist what he could take, and they told him there is nothing he could buy to help his situation without a prescription from his doctor. His sugar was up over 500. He took this product from my business and in two days it was back down to the mid 100's. I can't guarantee anything and this product is not FDA approved, but it is all-natural. If you would like more info send me a note or request me as a friend with a note and I will get in touch as soon as possible. I look forward helping you.

At times, the idea of a community "checking up" on the validity of posts would itself be utilized by Facebook marketers to manufacture a sense of authenticity and excitement around a product or website. One particularly prominent promotional poster "seeded" multiple diabetes discussion threads and wallposts with identical scripts asking other users to verify that their product's information was "too good to be true," e.g.:

> I just checked out this website about an alternative to diabetes medication. If anyone is willing to check it out [PRODUCT WEBSITE] could you please tell me what you think. I'd love to chat with someone who has tried it or knows of someone who has. It sounds too good to be true, so I'm guessing it probably is…but it makes so much sense!!

Thirteen percent of all posts contained specific requests for information, the majority of which sought personal information about diabetic Facebook users. Many of these requests were for research projects seeking to recruit trial subjects or asking diabetic patients and/or family members to fill out surveys regarding age, age of diagnosis with diabetes, use of insulin or oral medications, weight and/or body mass index,

comorbid conditions, exercise patterns, and diet behaviors. Product- or service-specific surveys then attempted to gauge the level of interest in specific types of coaching, lifestyle, exercise, dieting services and/or products. A limited number of posts attempted to recruit patients into phase II investigations of investigational new dugs (INDs) prior to FDA approval.

It was not possible, based on the information provided in the posts, to determine whether those requesting survey information represented university-based researchers, product R&D teams from industry, or corporate market research teams.

DISCUSSION

To our knowledge this is the first study to analyze, in detail, the content of health-seeking behavior and information-sharing on a popular social networking website. While several authors have used anecdote and speculation to celebrate or denounce the role of the Internet in diffusing the flow of disease-management information [14,15,] few existing studies have evaluated these claims with empirical data [16]. Our findings suggest that diabetes communities in Facebook contain a plurality of participants, including patients, family members, advertisers, and researchers, with divergent interests and modes of communication. These groups simultaneously serve as promotional spaces, support communities, repositories of recruitable research subjects, and venues for the solicitation and provision of forms of disease management-knowledge not necessarily available through more formal channels of professional consultation.

On several fronts our study offers tentative support of the proposed public health benefits of social networking media in the management of chronic disease. Users gain interpersonal and community support from wallposts and discussion threads, they access forms of specialized knowledge on diabetes management from peers, and can articulate positive but realistic self images as diabetic individuals and a mobilized diabetic community. Moreover, we found very little evidence of dangerous, misleading, or risky self-medication behavior being supported by Facebook pages for patients with diabetes.

However, inability to verify the identity of the poster—and the prominent use of Facebook pages for the promotion of non-FDA-approved therapeutic modalities — poses a significant problem to the trustworthiness of any single piece of information on this widely used online social networking tool. Beyond a level of screening for obscenity and hate-speech, there are neither editorial monitors nor fact-checkers on Facebook.

Given that most promotional materials take the form of first-person testimonials, it is difficult to know the authenticity of a subjective claim when a product or service is promoted. Moreover, is it unclear to what extent companies can be held liable for misleading or unsupported claims that are phrased as the personal expression of an community member [17,18]. Similarly, individuals claiming to be graduate students conducting thesis research may turn out to be market researchers. People claiming to be diabetics who have discovered a new cure-all product may represent fictitious testimonials generated by manufacturers and marketers. Nonetheless, at the core of this structure, there appears to be a number of individuals who regularly and repeatedly use Facebook as a community for collective identity-building, emotional and logistical support, and informal avenues for "street-level" disease-management information.

This study has several limitations. Social networking communities for diabetics may not be representative of groups focusing on other chronic diseases. We evaluated networking activity on Facebook, the world's largest social networking site, and not other sites such as Myspace, WebMD, and Twitter, which might yield alternate results. Our data were collected over a limited time period, and we may have missed more longitudinal or seasonal aspects of communication. This qualitative data was descriptive and exploratory, and not designed for formal hypothesis testing.

Despite the limitations, these methods allowed us to access a rich source of data to analyze an otherwise elusive research subject—the information-seeking and information-sharing behavior of chronic disease patients through social networking software. We find the promise of a community to support and educate others with similar conditions as well as the perils of an unregulated environment supporting substantial promotional and data-gathering activities. Clinicians should be aware of these strengths and limitations when discussing sources of information about chronic disease with patients. Policymakers should consider how to assure transparency in promotional activities, and patients may seek social networking sites developed and patrolled by health professionals to promote accurate and unbiased information exchange.

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