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Features of Online Health Communities for Adolescents With Type 1 Diabetes

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Abstract

The aim of this exploratory study was to examine diabetes online health communities (OHCs) available to adolescents with type 1 diabetes (T1D). We sought to identify and classify site features and relate them to evidence-based processes for improving self-management. We reviewed 18 OHCs and identified the following five feature categories: social learning and networking, information, guidance, engagement, and personal health data sharing. While features that have been associated with improved self-management were present, such as social learning, results suggest that more guidance or structure would be helpful to ensure that those processes were focused on promoting positive beliefs and behaviors. Enhancing guidance-related features and structure to existing OHCs could provide greater opportunity for effective diabetes self-management support. To support clinical recommendations, more research is needed to quantitatively relate features and participation in OHCs to patient outcomes.

Keywords

diabetes; adolescence; social media; Internet; social learning; problem solving

Diabetes self-management is a critical predictor of glycemic control (Hood, Peterson, Rohan, & Drotar, 2009). Self-management of type 1 diabetes (T1D) requires adherence to an intensive daily regimen that minimally includes monitoring blood glucose levels, estimating nutritional intake, and dosing insulin multiple times per day. These tasks typically take place around exercise, meals, and snacks and are difficult to maintain, with the majority of patients not meeting the recommended goal of a glycosylated hemoglobin (HbA1C) test value below 7.5% (Svoren et al., 2007; Wood et al., 2013). Adolescents face particular psychosocial challenges in self-management and show predictable declines in glycemic control during that developmental period (Helgeson et al., 2010). A wide range of psychosocial issues have been related to adolescent self-management such as stigma, social support, stress and burn-out, depression, peer relationships, and diabetes-related family conflict (Hilliard, Wu, Rausch, Dolan, & Hood, 2013; Ingerski, Anderson, Dolan, & Hood, 2010; Mulvaney et al., 2011; Palladino & Helgeson, 2012).

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One of the most influential and effective frameworks used to guide intervention design in diabetes is Social Cognitive Theory (SCT; Bandura, 2003). This theory explains the acquisition and maintenance of health behaviors through the interaction of cognitive, behavioral, and environmental factors. Research has reliably related social cognitive factors in T1D youth as predictors and correlates of improvement in self-management and glycemic control, such as diabetes knowledge, coping and problem solving, self-efficacy, social support, and depression (Antal & Wysocki, 2008; Grey et al., 2013; Grey, Whittemore, & Tamborlane, 2002; Koontz et al., 2010; Mulvaney, Rothman, Wallston, Lybarger, & Dietrich, 2010; Rovner et al., 2012). One reason SCT has been widely translated into health behavior programs is the specification of mechanisms of change, such as modeling and guided mastery (Glanz, Rimer, & Lewis, 2002). However, while theory-driven approaches have been shown to improve diabetes self-management, the reach of such interventions has been limited, dissemination has been slow, and access has typically been limited to research participants (Garfield et al., 2003).

With the evolution of Web 2.0 functionality and Internet penetration, web-based programs are increasingly utilized as a mechanism by which to incorporate social, interactive, and guided behavior change processes. There is increasing evidence to support the feasibility and efficacy of the Internet as a modality for catalyzing behavioral change in the self-management of pediatric chronic illness, including diabetes (Grey et al., 2013; Mulvaney et al., 2010; Ritterband et al., 2008; Stinson, Wilson, Gill, Yamada, & Holt, 2009; Whittemore et al., 2013). Currently, online support for individuals with diabetes largely takes three forms: (a) non-interactive informational websites that provide diabetes facts and clinical recommendations, (b) websites typically designed as a time-limited program with a guided set of psycho-educational experiences to support behavioral change goals, and (c) online health communities (OHCs) created as virtual environments for individuals with shared health conditions and goals to connect through a variety of social media experiences (van der Eijk et al., 2013). The second “programmable” uses of the Internet have largely been designed and utilized by behavioral scientists funded through research grants. These programmatic sites tend to be more structured, based on research, and focused on associating specific configurations of online experiences with self-management and glycemic control.

In comparison, there are a number of OHCs readily accessible to young individuals with diabetes. However, to the authors’ knowledge, no research currently exists to document website features of OHCs available to adolescents with diabetes. Some qualitative research now exists to document the content of adult exchanges related to diabetes on social networking websites (Greene, Choudhry, Kilabuk, & Shrank, 2010; Stuckey, Olmsted, Mincemoyer, & Gabbay, 2012; Zhang, He, & Sang, 2013). The focus of this research has been primarily on accuracy of information and safety, opposed to utility for behavior change (Weitzman, Cole, Kaci, & Mandl, 2011).

There has been little research to document the features currently integrated into readily available websites and how they relate to evidence-based methods to support improved self-management. The purpose of this study was to understand the potential utility of OHCs for

improving adolescent T1D self-management by identifying and characterizing features of sites that are available to adolescents.

Method

The methods for this study involved two phases: (a) identifying a set of the most relevant English-language OHCs for patients with T1D, including those outside of the United States; and (b) identifying and coding OHC features or functionalities.

Sampling

In the first phase, a sample of sites for consideration was initially found using the Google search engine. Two different Boolean searches were conducted in March 2013, combining sets of synonyms for “teen” (e.g., teenager, adolescent, youth), “type 1 diabetes” (e.g., T1D, diabetes mellitus, juvenile diabetes), and “social network” (e.g., social networking, virtual community, forum). The first search consisted of the former two sets of terms and the second consisted of the latter two sets of terms. Together, the two searches yielded more than 22 million results. Two of the authors independently reviewed the top 50 search hits and determined if they were English-language websites and met either of the following inclusion criteria: (a) a stand-alone diabetes website dedicated to adolescents with a section specific to T1D or (b) a stand-alone diabetes website not dedicated to adolescents with a section specific to T1D.

Search hits were then independently reviewed and dichotomously scored by two of the authors based on the following operational definition of an OHC for this study: a web-based experience that allows individuals with T1D to create their own profiles and connect with each other bidirectionally (e.g., chats, forums). Discrepancies were discussed, and sites were only included for review if they were OHCs that clearly included diabetes and were accessible to adolescents with T1D. All sites were reviewed over a 4-month period (March through June, 2013). To ensure that our list was exhaustive and complete, we elicited additional recommendations from pediatric diabetes experts on a professional listserv (Behavioral Research in Diabetes Group Exchange, BRIDGE) and included any sites that were not previously identified in our search. Diabetes-related blogs, as well as groups that exist within other social networks not focused on health (e.g., Facebook), were excluded. Based on the above process, 24 sites were ultimately identified and initially characterized in terms of utilization, certification, and access to T1D adolescents.

Identification and Coding of Website Features

The second phase consisted of identifying and coding OHC features. Two coauthors participated in an iterative process of identifying, characterizing, coding, and refining the set of site features. Any discrepancies in coding were resolved by discussion with the third co-author. All 24 sites were reviewed; however, 6 were excluded from further analyses for the following reasons: 3 were part of other sites already included in the review (jdrf.org, kids.jdrf.org, and diabetes.org/living-with-diabetes/parents-and-kids/planet-d/); 2 were primarily informational resources that did not meet our OHC criteria (diabeteshealth.com and collegediabetesnetwork.com); and 1 was under construction during the time of our

review (d1.org.au). OHC features were sorted based on their similarities in purpose and functionality and then organized into one of the following five categories: social learning and networking, information, guidance, engagement, and personal health data sharing. Social networking and social learning features were combined into one set, although not all social networking features promote direct social learning.

Results

We analyzed a total of 18 diabetes OHCs. Three of these OHCs (patientslikeme.com, diabeticconnect.com, and inspire.com) provided diabetes-specific communities within a larger *pan health* site that served multiple illnesses and health concerns. Of those 18 sites, 16 (89%) were in the top 50 Google search hits and 2 other sites were recommended for inclusion in the study by pediatric diabetes experts (community.diabetes.org and youngdiabetics.org). Table 1 shows each site included in our review ordered by Google PageRank, a weighted measure of website presence in the Internet scaled from 1 to 10, where a 9 or 10 represents a highly accessed site such as google.com or apple.com (Page, Brin, Motwani, & Winograd, 1999). Average PageRank across all sites was 4.4 ($SD = 1.5$) with a range from 2 to 7. In terms of legal structure, we were able to obtain information about 15 of the OHCs—of those, 7 (47%) were for-profit and 8 (53%) were non-profit. We found that less than half of the OHCs were certified by the Health On The Net Foundation (HON), a non-profit accredited by the Economic and Social Council of the United Nations that evaluates trustworthiness and reliability of health-related sites (Boyer, Selby, Scherrer, & Appel, 1998). None of the OHCs in our study incorporated all features across all five of the feature categories (i.e., social learning and networking, information, guidance, engagement, and personal health data sharing). However, all sites incorporated at least 25% of social learning and networking features. Specific features for each category are described in more detail in the next section.

While we reviewed sites accessible to T1D adolescents, we found no OHC that verified that a user has been diagnosed with diabetes (e.g., via clinician verification). Users were asked to identify their relationship to an individual with diabetes on most sites. Almost three quarters of the OHCs (13, 72%) allowed new users to identify themselves as a person with diabetes or a member of the individual's family, support network, or health care team. All but two sites verified age through self-report, and myglu.org used a delegate system in which a parent approved access for a minor.

Features of Diabetes OHCs

We identified features that could potentially support evidence-based diabetes management and determined if and how each of these features was made available to each of the sites we reviewed. Features were categorized by topic (i.e., social learning and networking, information, guidance, engagement, and personal health data sharing). Table 2 summarizes the proportion of OHCs with specific features, organized by category.

Social learning and networking—While no diabetes OHCs implemented all the social features we identified, all sites did implement at least one. These features provided either one-to-one or one-to-many communication. Almost all OHCs allowed for one-to-one

communication via private messaging between users, a functionality similar to email; however, real-time chatting or instant messaging (IM) were less common features, available in one third of the sites. Sites incorporated the following one-to-many communication mechanisms: a mechanism to post instant feedback on others' online activities (e.g., a "like" button or similar social plug-in), ability to publicly comment or "shout" on others' posts, ability to post status updates to one's own profile, blogs or online journals, and an activity feed displaying a user's recent site activity.

Only two sites (childrenwithdiabetes.com and diabetes.co.uk) included specific sections on the site dedicated to sharing personal narratives and stories about diabetes, while more than half allowed users to share their own stories through their personal profiles (e.g., via "About me" or "My diabetes story" sections).

A forum or discussion board was the most common social feature of OHCs with 100% of sites reviewed here providing this option to users. Other common social communication features included tools to allow one to "friend" or "follow" others. For example, myglu.com allowed users to form "bonds" with other users. Some sites also incorporated a way for users to create and/or join groups of users with similar backgrounds and interests within the site. About half of the sites provided the capability for users to search the site for "friends" or other users with similar characteristics.

While all sites incorporated various means of promoting social interactions between users, the majority also had external groups and/or feeds on other popular social media, such as Facebook (14, 78%) and Twitter (15, 83%). Of those with Facebook groups, the number of "likes" was highly variable, ranging from less than 200 to more than 320,000. Less than half of the sites reviewed had YouTube channels (8, 44%), Pinterest accounts (4, 22%), and/or mobile apps (5, 28%). Most sites (14, 78%) featured the capability of "liking" or sharing site content on other social media, such as Facebook or Twitter.

Information—Most sites included various ways to share information about diabetes with their users. The most common was a section for diabetes-related news in the form of staff-written articles or a blog (14, 78%). Half of the sites included the following: a regularly scheduled email newsletter, a section for diabetes-related didactic videos, or product reviews written by staff and/or users. Diabetes1.org, for example, included a section of the website that featured videos to provide basic information about developing an exercise schedule, choosing the right blood glucose meter, and long-term risks of diabetes. Type1Parents.org posted product reviews written by staff on pump accessories such as pouches and armbands.

Guidance—Guidance was provided through either one-to-many or one-to-one communication features. Five sites included a way for users to "ask the experts" questions about diabetes, such as through a public or private message to a certified health care professional. Site features that provided individual guidance were less common. Coaching and mentoring were features found in two sites, and coaching capabilities were limited. One other example of structured guidance was typeonenation.org's "Adult Type 1 Toolkit," which was designed to be an "interactive online road map" for adults with T1D, but was

available to adolescents as well. Review of the toolkit revealed a step-by-step, didactic model of learning with limited interactive or personalized functionalities.

Engagement—Less than half of the OHCs included in our review incorporated features that could promote user engagement, such as gamification or social recognition. Diabetes-related polls and quizzes generated by the site or by users were available on fewer than half of the sites (44%), and games and challenges were found on one third of the sites. Seven sites (39%) awarded social recognition points or titles, visible to all users, for various forms of participation. An example of social recognition was the use of “badges” on diabeticconnect.com; badges are awarded to users who engage in the site by, for example, participating in discussions, reviewing treatments, and providing support through comments or virtual “hugs” to other users. Seven sites included roles for OHC staff, diabetes patients, and/or experienced users to act as community managers or advocates to help users navigate the site and leverage network connections to help with diabetes management. Just less than half of the sites posted diabetes-related events, such as fundraisers, camps, in-person conferences, and online chat sessions with celebrities.

Personal health data sharing—Fewer than half of all OHCs included tools for monitoring one’s own health data. Some sites included a health calculator for users to determine their body mass index. Approximately one third of the sites allowed users to report their HbA1C and/or pump information as part of their personal profiles. Two sites (11%) collected information about medications, nutrition, and/or exercise. PatientsLikeMe was the only OHC to collect information about all three of these aspects of diabetes management, and was one of the few examples of a more data-driven OHC that allows for users to monitor their own personal health activity as well as that of others.

Discussion

Our exploration of online diabetes communities (OHCs) available to adolescents with T1D revealed five categories of features: social learning and networking, information, guidance, engagement, and data sharing. The most prevalent set of features available to OHC users were those that supported social learning and networking. Opportunities for communication between users took several forms. Most social networking features we identified not only supported the one-to-many communication model used more commonly in today’s emerging technologies (Steele, 2013) but also included opportunities for one-to-one communication. While some features supported the initiation of new social connections, such as creating or joining a group or finding a “friend,” most were focused on making or maintaining social connections through publicly available comments or private messaging.

Ongoing social support plays an important role in chronic disease management and is a recommended component of diabetes education (Dale, Williams, & Bowyer, 2012; Funnell et al., 2011). Social support has been linked to improved self-management and A1C in pediatric diabetes, while peer-based conflict has been related to worse outcomes (Malik & Koot, 2011; Palladino & Helgeson, 2012; Skinner, John, & Hampson, 1998). The social networking features observed in these OHCs may facilitate social support for those living with diabetes. Even a few features that allow for online exchange of information, coping

strategies, and emotional support can improve a diabetes patient's perception of social support (Barrera, Glasgow, McKay, Boles, & Feil, 2002).

However, social networking may not lead to social support and may not result in improvements in positive well-being or self-management. The benefits of social networking may depend on individuals' integration in a given network and the degree to which they know each other in-person or "offline" (Hampton, Goulet, Rainie, & Purcell, 2011; Reich, Subrahmanyam, & Espinoza, 2012). In addition, recent studies suggest that information exchanged through social networking is not always credible (Greene et al., 2010), and the quality and safety of diabetes social networks is variable (Weitzman et al., 2011). It appears that the limitations of social networking for health behavior change on diabetes websites, as currently implemented, are primarily based on how those features are used by OHC members and how or if content is moderated or guided.

Website features more representative of social learning rather than social networking mechanisms, such as modeling behaviors via first-person stories, normalization of commonly encountered challenges through user polls, and other vicarious learning processes such as "liking" others' status updates were frequently integrated into the websites. Similar to social networking, social learning features provide the scaffolding for learning, but are not necessarily guided toward modeling or sharing productive behaviors or information. For example, we found that OHCs rarely solicited and compiled first-person narratives that depicted members' experiences overcoming barriers to diabetes self-management. Without purposefully guided content, social learning may take a negative direction when unhealthy behaviors or negative attitudes are modeled and shared (Moreno et al., 2009).

A large portion of OHCs provided information about diabetes through articles, news, or informational blogs. Knowledge about diabetes forms the basis for successful self-management; therefore, the provision of news, diabetes information, and other available information resources is a strength of diabetes OHCs. Diabetes knowledge and health literacy such as numeracy skills, understanding the role of carbohydrates in blood glucose control, and the consequences of diabetes have been related to improved outcomes (Koontz et al., 2010; Mulvaney, Lilley, Cavanaugh, Pittel, & Rothman, 2013; Rovner et al., 2012; Wysocki, Lochrie, Antal, & Buckloh, 2011). Because of the complexity of diabetes regimens, and the fact that diabetes technologies are rapidly evolving, information regarding pumps, meters, and mobile applications provides practical information and resources for improving self-management.

Features related to providing guidance were the least prevalent within these OHCs. Although some OHCs provided a forum, very few OHCs provided moderated discussion or individualized support in the form of direct online access to a diabetes professional or a mentor. A wide variety of research on mentoring and coaching, using peers, paraprofessionals, and professionals in diabetes have generally provided support for those programs (Funnell, 2010; Nansel et al., 2007; Nijland, van Gemert-Pijnen, Kelders, Brandenburg, & Seydel, 2011). In online settings, mentors, guides, and moderators can provide the necessary structure and direction to shift an unproductive or negative social networking process into one that could positively influence social support and skill building.

Mentoring or coaching features could be used for a variety of purposes, including self-management problem solving and more focused emotional support than one might receive through an open forum.

Engaging youth in diabetes care is one of the central challenges in health behavior intervention design. The features most clearly utilized for engagement involved gamification such as point structures. Although in its infancy, incorporation of interactive elements related to gamification, such as points, competition, and vicarious avatar-based decision making, is a promising means to improve engagement, and possibly knowledge and self-management behaviors (DeShazo, Harris, Turner, & Pratt, 2010; Glasemann, Kanstrup, & Ryberg, 2010). Not surprisingly, engagement features served dual functions to the extent that they incorporated diabetes information. In addition, given the central role that perceptions of social “relatedness” play in human motivation (Ryan & Deci, 2000), it could be argued that many of the social networking and learning features were also engagement features.

Vibrant social online interactions are dependent on user engagement and the willingness to share personal experiences. Websites such as patientslikeme, the availability of new wireless technologies, and popular movements such as “the quantified self” have focused on the willingness and value of monitoring and sharing personal health information (PHI) and data with others. A relatively small number of OHCs reviewed here allowed or promoted sharing such PHI. While little diabetes research exists in this area, research with other chronic illness populations indicates that sharing PHI with similar others may promote social support and engagement with health care decision making (Wicks et al., 2010). As interest and research in this area grow, diabetes-focused OHCs will likely provide enhanced features to share and learn from personal health data.

There are several limitations to the current study. Feature categories were not mutually exclusive. Some features related to engagement were not content-specific, but more process-oriented and thus straddled other feature categories. Similarly, this study did not examine website content. We identified features and processes available on OHCs, but not how they were being used. This distinction is important because, although we identified evidence-based behavior change mechanisms, those mechanisms could be used to share and reinforce either positive or negative beliefs and behaviors. Finally, OHCs and their features are not static. It is possible that site features, and even the sites themselves, were removed or modified after our observation period.

In conclusion, results indicated that OHCs have incorporated at least some evidence-based features that have been associated with improvements in diabetes self-management. The scaffolding and structure for social learning features such as modeling were frequently integrated, but lacked the focus or guidance to translate those reliably into structured or positive learning experiences for users. One challenge in leveraging the power of a publicly available website is finding a way to simultaneously promote engagement, social interaction, and user-generated content, while guiding interactions and content in a productive direction that could impact actual health outcomes. Providing automated guidance for discussions and activities may be more feasible for large OHCs with greater volume and opportunities to

reach out to members with similar problems. Clinicians seeking guidance on the value of these resources for youth with T1D have reason to be cautiously optimistic regarding the potential of OHCs as reliable patient resources. However, it remains to be too early to provide definitive recommendations for clinicians regarding specific websites without knowing how patient outcomes data are associated with OHC use. Additional research is needed to characterize the content exchanged within and across OHCs, the nature of how and how often features are being utilized, and the relation of website engagement with self-management behaviors and glycemic control.

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Table 1

Overview of Diabetes OHCs Reviewed, Ordered by PageRank($N = 18$)

Name of OHC	Website URL	PR ^a	Legal Structure	HON ^b	Creation ^c	Feature Categories (No. of Features; %)				
						Social Learning and Networking (12)	Info (4)	Guidance (2)	Engagement (5)	PH ^d (6)
PatientsLikeMe	Patientslikeme.com	7	For-profit	Yes	2006	83	75	0	80	86
American Diabetes Association	community.diabetes.org	6	Non-profit	No	2009	25	50	50	40	14
TuDiabetes	www.tu diabetes.org	6	Non-profit	Yes	2008	75	100	0	60	43
Children With Diabetes	childrenwithdiabetes.com	6	Non-profit	Yes	1996	50	100	50	60	0
TypeOneNation	Typeonenation.org	6	Non-Profit	No	2013	83	50	50	20	14
Diabetic Connect	Diabeticconnect.com	5	For-profit	No	2008	67	75	50	60	14
dLife	dlife.com	5	For-profit	Yes	2011	83	100	50	60	14
Diabetes Daily	Diabetesdaily.com	5	For-profit	No	2005	83	75	0	60	71
Diabetes forums	Diabetesformus.com	4	NA	No	2002	58	0	0	20	14
Reality Check	realitycheck.org.au	4	Non-profit	Yes	2009	25	0	0	0	0
Diabetes.co.uk	diabetes.co.uk	4	NA	No	2001	58	75	0	20	71
diabetes1.org	diabetes1.org	4	For-profit	Yes	2005	33	100	100	100	14
The Diabetic Network	diabeticnetwork.com	4	For-profit	No	NA	50	100	0	20	14
Glu	myglu.org	3	Non-profit	No	2011	50	25	0	50	57
Type 1 Parents	type1parents.org	3	Non-profit	Yes	2007	25	25	0	20	0
South Texas Juvenil Diabetes Association	stjda.org	3	Non-profit	No	2013	33	50	0	20	0
YoungDiabetics.org	Youngdiabetics.org	2	NA	No	2008	25	25	0	20	0
Inspire	inspire.com	2	For-profit	No	2011	75	0	0	20	0

Note. OHCs and their web addresses are shown with general information about each site and proportion of features in each of the five categories identified in this study. OHC = online health communities; NA = not applicable.

^aGoogle PageRank (PR).

^bHealth on Net certified (HON) site.

^cEstimated year of website's creation based on the Internet Archive Wayback Machine.

^dPersonal Health data sharing (PH).

Table 2

Diabetes OHC Site Features, Respective Feature Categories, and Proportion of Sites With a Given Feature.

Categories and Specific Features	Number of Sites (%)
Social learning and networking	
Forum	18 (100)
External Facebook and/or Twitter account	16 (89)
Private messages	14 (78)
“Friend” or “follow” other	12 (67)
“Friend” search tool	10 (56)
Provide feedback	10 (56)
Blog	9 (50)
Activity feed	8 (44)
Groups	8 (44)
Chat/IM	6 (33)
Status update	5 (28)
Stories or narratives	2 (11)
Information	
Articles/news/blog	14 (78)
Newsletter	9 (50)
Reviews of diabetes products	9 (50)
Videos	9 (50)
Guidance	
Ask the expert	5 (28)
Online coaching/mentoring	2 (11)
Engagement	
Site-sponsored in-person and/or online events	8 (44)
Polls/quizzes	8 (44)
Community managers/advocates	7 (39)
Social recognition points for site activities	7 (39)
Games/challenges	6 (33)
Personal health data sharing	
Health calculators	8 (44)
Glucose values sharing	6 (33)
Pump information	5 (28)
Medications	2 (11)
Nutrition	2 (11)
Exercise	2 (11)

Note. OHCs = online health communities; IM = instant messaging.