


June 2016

Glu: An Online Type 1 Diabetes Information Community

Stefanie Witt

San Jose State University, stefa.witt@gmail.com

Follow this and additional works at: <https://scholarworks.sjsu.edu/ischoolsrj>

 Part of the [Health Communication Commons](#), [Health Information Technology Commons](#), and the [Library and Information Science Commons](#)

Acknowledgements

San Jose State University School of Library and Information Science INFO 200: Information Communities Dr. Kevin Bontenbal

Recommended Citation

Witt, S. (2016). Glu: An online type 1 diabetes information community. *SLIS Student Research Journal*, 6(1). Retrieved from <http://scholarworks.sjsu.edu/slissrj/vol6/iss1/3>

This article is brought to you by the open access Journals at SJSU ScholarWorks. It has been accepted for inclusion in School of Information Student Research Journal by an authorized administrator of SJSU ScholarWorks. For more information, please contact scholarworks@sjsu.edu.

Glu: An Online Type 1 Diabetes Information Community

Abstract

This research paper examines the online health community Glu (MyGlu.org), a type 1 diabetes social media site. Type 1 diabetes is a chronic medical condition that requires constant and specialized medical attention. Online health communities like Glu, are an important part of maintaining a healthy lifestyle for many of its members. This study discusses the composition of this information community, the motivations of its members, and the benefits members gain through their participation. It describes the major characteristics of the community and focuses on the information needs of type 1 diabetics. It concludes with reflections on how libraries and LIS professionals can better serve the information needs of health communities like Glu and accommodate their needs in the physical space of the library.

Keywords

information communities, type 1 diabetes, online health communities, chronic health conditions

Acknowledgements

San Jose State University School of Library and Information Science INFO 200: Information Communities
Dr. Kevin Bontenbal

About Author

Stefanie Witt is a graduate student in San Jose State's iSchool. She plans to graduate in Fall 2016.

Glu (www.MyGlu.org), a play on the words glucose and glue, is a health focused online community for people living with type 1 diabetes (T1D). Unlike the more common metabolic disorder known as type 2 diabetes that most are familiar with, the Mayo Clinic defines T1D as an inflammatory autoimmune disease that occurs when the body's own immune system, which normally fights harmful bacteria and viruses, mistakenly destroys the insulin-producing islet cells in the pancreas. When T1D occurs, the body has no insulin to let glucose into the cells, so sugar builds up in the bloodstream, where it can cause life-threatening complications (Collazo-Clavell et al., 2014). According to leading research by the American Diabetes Association (2014), T1D accounts for five percent of diabetes cases worldwide. Despite active research, the cause of T1D is unknown and has no cure. This paper discusses the composition of Glu and touches on the larger online type 1 diabetes information community, the motivations of its members, and the benefits that members gain through their participation in information exchange. Interviews with members of Glu provide insights into the major characteristics of the community and the real information needs of type 1 diabetics. The paper concludes with reflections on how librarians can better serve the information needs of chronic health communities like Glu and integrate such communities into library services, programs, and spaces.

In line with the definition of an online information community outlined by Fisher et al. (2003), Glu fosters social connectedness and collaboration among diverse information providers. Glu (2013a) describes itself as “an active and diverse type 1 diabetes online community designed to accelerate research and amplify the collective voice of those living with T1D.” Community members are mostly adults living in North America; however, young adults 13 years of age and older are allowed to join the community. Members of Glu connect with others living with T1D, take an active role in community discussions and research on their disease, and learn from the wealth of rich information found within the pages of the site (Glu, 2013a). Members access the site by creating a customized profile through which they can connect with others. Like more familiar social networking sites, Glu allows members to add friends, update statuses, and post responses to other members' pages.

Also in line with the findings of Fisher et al. (2003), one of the most compelling ways this online information community exploits the information sharing qualities of technology and yields multiplier effects for its stakeholders is through the gathering of clinical research from its diverse members via a social media platform. The Glu website posts a daily question that polls all community users that are online. Responding to the question is not mandatory, but the answers given are logged anonymously and used for T1D research. Within the online community, the poll data is updated continuously, revealing the results and individual members' answers to the entire community, sparking debate, spreading knowledge, and encouraging connectedness within the community. Short answer polling is another method used by the researchers behind Glu, which uses the same techniques and reinforces these same communal qualities; members are allowed to voice their expert opinions and experiences living with the disease as they discuss key issues with others like them while also contributing to research that works towards providing a cure for their chronic medical condition.

As a rare form of diabetes that often causes feelings of isolation, Glu allows type 1 diabetics around North America to meet, communicate, and share personal experiences with one another, helping them to overcome the feelings of isolation often experienced by

sufferers of this rare disease. The community also informs members of clinical research opportunities outside of Glu, recent articles on T1D, individualized group discussion boards, and online events such as recipe exchanges. With these offerings, formed as they are around members' needs, the site promotes community building as defined by Fisher et al. (2003), enabling participants to transcend real and perceived barriers to information sharing. A community for people living with T1D, the focus of Glu is to expand medical research, advocate for those living with the chronic autoimmune disease, and provide an opportunity for their real-life supporters, such as parents, guardians, and spouses of type 1 diabetics, to make accounts and take part in the information sharing of the community.

Literature Review

Limited research has been done on T1D-specific online communities, as more focus has been placed on researching online health communities (OHCs) in general. Many schools of thought have emerged from the writings on what defines such a community and thus a T1D-focused online community such as Glu. In their analysis of an online T1D community based in the United Kingdom, authors Armstrong et al. (2011) define OHCs in relation to their members, explaining that OHCs are “shaped in important ways early on by the community users, including how the character and focus of discussion is formed, and how both information and users can be constructed as authoritative and reliable” (p. 347). Newman et al. (2011) choose to define online health communities by purpose, explaining that members join them in pursuit of emotional support, motivation, accountability, and advice regarding their health goals. Both definitions support this paper's research findings on Glu.

In line with Newman et al., analysis by Gilbert et al. (2012) also defines online T1D communities in relation to purpose, honing in on their ability to serve as peer support programs. In their study of 18 OHCs specifically related to T1D, authors Ho et al. (2014) define these communities as opportunities for effective health management, providing members with a chance to share health information, network, engage, and learn. However they are referenced, the literature unanimously concludes online health communities provide members with emotional support and imperative health information while helping them deal with the stress of living with a chronic disease such as T1D.

The literature sets forth many pros and cons that should be considered by T1D patients when deciding whether or not to participate in an OHC. Within the set of pros, an overarching theme arises from the literature: That sufferers of T1D face emotional hurdles and information challenges when managing their chronic illness and that OHCs such as Glu can empower patients to gain better control over their health. Armstrong et al. (2011) emphasize that “day-to-day management is carried out almost exclusively by the patient and can often be complex and emotionally challenging, meaning many do not achieve good control over their blood glucose levels” (p. 348). Gilbert et al. (2012) conclude that “. . . uncertainty and knowledge of the potential for death or disability can compound psychological strain. There can be a tangible burden associated with the considerable time, energy, and focus required to establish and maintain metabolic control . . .” (p. 180). Ho et al. (2014) echo this same theme in their findings on online T1D communities for adolescents and explain, “a wide range of psychological 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” (p. 1184). In the face of overwhelming stress caused by chronic illness, OHCs offer type 1 diabetics

empowerment through low-cost information exchange and emotional support.

That is not to say the literature has found OHCs to exist without controversy. Ho et al. (2014) take issue with the fact that none of the T1D online communities they analyzed require any type of verification that users actually have been diagnosed with diabetes, the community of Glu included. Gilbert et al. (2012) find that members of type 1 diabetes OHCs also complain about gossip spreading and “criticism of health professionals,” as well as antagonism towards type 2 diabetics, conflicts of opinion, censorship, and “feeling judged by other participants” (p. 186). Newman et al. (2012) find that while OHCs provide many benefits, community members do have complaints: “Some participants felt that goals such as emotional support and accountability were best served by people who knew them personally as opposed to only through their online identity” (p. 348). Bartlett and Coulson (2010) also address the “lack of strong ties” among OHCs members, which “can make flaming or hostile comments more likely” (p. 113). However, quoting research findings by Uden-Kraan et al., Bartlett and Coulson concede that hostile messages are rarely exchanged while accurate information often is, concluding that OHCs are “a viable medium for support” (p. 113).

In terms of gaps or biases, the literature on OHCs indicates a need for further research on how chronic illness is affected by positive and negative relationships and social experiences. Chen (2012) points out previous studies on OHCs highlight further examination of the “social aspects of the illness experience” (p. 254) is needed beyond the caregiver and patient role. Though established research on OHCs in general certainly correlates with the type of information sources and services this unique community requires, research on the diabetes online community is significantly lacking.

Methodology

In order to understand the information needs of the online type 1 diabetic community of Glu, this research began with an examination of secondary sources. An initial search of “diabetes online community” in the King Library databases yielded few hits, only one of the results being peer-reviewed. A broadened search of “online health communities,” provided over 100 scholarly articles on OHCs; however, few focused on the diabetes online community. The articles came from a range of databases including: Academic Search Premier, Library, Information Science & Technology Abstracts, PsycINFO, and Business Source Complete. Recently published research was sought out by interviewing an endocrinologist who recommended the biomedical database PubMed, which yielded articles focused on the impact social support has on the overall health of members participating in T1D online health communities.

While some secondary sources of information focused on certain aspects of the diabetes online community and OHCs in general, few to none have covered the full scope and depth of a specific online type 1 diabetic community, much less Glu itself. After consulting the King Library databases and PubMed, searches were conducted on Google Scholar and Google, which yielded helpful results, including articles from the British Medical Journal (BMJ) and the American Diabetes Association’s Journals for Professionals; these sources focus on the many aspects of treating, living with, and researching treatments for individuals with type 1 diabetes.

In addition to secondary sources, this paper includes interviews with four Glu community members. These interviews give insight into the nature of the information persons living with T1D seek and the types of resources they use. The Glu interviewees

vary in age, sex, location, and length of membership in Glu. All members are type 1 diabetics (as opposed to supporters of people living with T1D), of the same race (white non-Hispanic), and strangers outside of the Glu community. All members of the community answered the interview questions via an open forum on the Glu website and chose to remain anonymous. This firsthand data is very revealing of the member experience and gives insight into the importance of online information exchange to members of the T1D community. This insight correlates with the potential power of OHCs proposed in the scholarly literature, and is revelatory of the T1D online experience in particular.

Motivations, Benefits, and the Needs of the Community

Glu exists as an online health community that connects people living with T1D to each other and to researchers in order to do two main things: allow type 1 diabetics to obtain and share information with others like them and to obtain and share information with researchers trying to find a cure. The motivations of and benefits to the community are just that, individuals with T1D are able to obtain more information about their condition, not just in terms of treatment, but for all the different aspects of living with the chronic disease, sharing information with everyone from experts to the newly diagnosed. Here the term expert is not solely applicable to medical professionals, but also to experienced type 1 diabetics who share their knowledge, advocate, and exchange information with others in the online community through forums and postings.

Topics that are frequently discussed on Glu include: How do you go to the beach or wear a bathing suit with an insulin pump? Should you share the fact that you're type 1 diabetic on a first date or would that scare away your date? If not, how long should you wait before telling a significant other about your condition? Is it wrong to conceal that you have T1D on job interviews? What are the real-life pros and cons of using a particular insulin pump? Clearly, this type of information is outside the scope of a patient's endocrinologist or typical healthcare team; the answers come from the experience of members living with the chronic illness. In their study of health-related virtual communities, Ilioudi et al. (2014) point out that benefits of the community are cost-effective and instant health services such as building social connections with peer patients, sharing experiences, setting common goals, and helping each other find solutions to common problems within the online patient community: "Chat rooms, group meetings, and consultations are all virtually brought in the patient's home, anytime, anywhere." (p. 9).

This kind of interaction with other type 1 diabetics supplements gaps in Glu members' current treatment plans and has the potential to offer the emotional support they may not be able to receive elsewhere. Oh and Lee (2012) refer to this type of patient empowerment as computer-mediated social supports and propose that "as patients spend more time in an online community and communicate with other members more frequently, they have more opportunities to receive CMSS from fellow members of the same online community" (p. 31). Thus, information is exchanged and different needs are met in a cyclical manner; members of the community are motivated by the therapeutic sharing of their experience and by having their voice heard, as other members simultaneously benefit from hearing advice from peers and adopting new methods of treatment.

It should also be pointed out that members are motivated to join Glu for reasons

outside of emotional support. In their study of OHCs, Massimi, et al. (2014) found that:

Another reason for joining was to develop a better understanding of the condition more generally, without necessarily seeking emotional support. . . they [participants] were interested in obtaining scientific (and non-scientific) information about their condition, and worked to develop an expertise on the topic through both study and personal experience (p. 1496).

As found in the following interviews, Glu provides members a range of benefits, from empowerment and social support to better understanding of the disease through reliable sources including peer experts and scientifically backed data. Due to Glu's involvement in clinical research, its benefits to members also include allowing them to actively give back to the community by participating in current research on curing and treating T1D. "Glu is part of the T1D Exchange, a nonprofit organization with a mission to improve the lives of people touched by T1D by facilitating better care and accelerating new therapies through a collaborative data collection and sharing network" (Glu, 2013b).

The Glu Community's Perceptions of Information Services

The Glu website is composed of forums, research surveys, informative articles, and social media features such as member profiles, groups, and status updates around which people living with T1D and their supporters may connect. In their research on the user-generated web and online information sharing, authors Flanagin et al. (2013) state, "The capacity of the Web to facilitate information sharing among disaggregated individuals is among its most important features" (p. 1). Four individuals in the Glu community report finding important information and genuine support from other Glu members despite living in separate locations across North America and never physically meeting. The importance of such connections are pointed out by the research of Massimi et al. (2014): "While the exact mechanisms by which social relationships affect health remains unclear, nearly 30 years of research has consistently demonstrated that they have a powerful effect on physical and mental health, and may extend survival" (p. 1492). This research aims to examine some of the information resources used by the community and the community's perceptions of those sources. It should be stated that the findings refer to the information-seeking behavior and information sources utilized apart from the patient's endocrinologist and other healthcare team members.

In line with interview findings in this research, Flanagin et al. (2013) state that "One of the most valuable features of information pools is that they enable widely dispersed and diverse users to seek out and interact with others who are different from the people they may encounter regularly offline" (p. 1). The interviews reveal how important online information exchanges, or what Flanagin et al. define as "information pools" as opposed to brick and mortar libraries, are to members of the T1D community.

Interviewee 1 has been a member of Glu since 2014. He is an engineer in his late 50's residing in Texas. He provided the most information about how he manages his disease outside of conferring with his doctor. He lists diabetes associations such as the ADA, books, the diabetes online community other than Glu, and blogs as his main sources of information. Out of all the online sources, he prefers Glu because the community is "active and filled with interesting topics and research on type 1 diabetes." He also states his favorite aspect of Glu is that there is "always something new each day and I love the surveys." His interview makes clear that he highly values sources that

reference current clinical research on T1D, as well as the opportunity to share the vast experiences of others, stating that “. . . being an engineer, everything interests me. I love all the different perspectives, even if they really don't affect me and I love sharing my own [perspective].” This individual's viewpoint is in line with the findings of Flanagan et al. (2013): “This sense of shared group membership may help sustain these communities by encouraging users to trust in information sources and their input, and by encouraging them to also contribute information to these pools themselves” (p. 2). On Glu, information is a cycle; the more people share, the more others want to also share.

Interviewee 2 has been a member of Glu since 2014. She is a 29-year-old mother of one residing in Quebec, Canada. Interviewee 2 says she uses Glu almost exclusively for research on her disease and can no longer relate to information given by diabetes associations because, “The Canadian Diabetes Association is very type-2 oriented and JDRF [Juvenile Diabetes Research Foundation] is very child-oriented, that's why I turned to Glu!” For any other information she needs, including what she refers to as “scientific articles on T1D research,” she relies on Google. When speaking more about her experience of obtaining information from other members in the Glu community, she says that she “. . . started exploring and sharing on myglu.org two months ago and have already learned a ton of things from other type ones! I find this very exciting!” Her excitement matches the findings from Flanagan et al. (2013): “. . . potential content contributors may be more motivated and likely to contribute useful material to information pools when they appear to be populated and used by similar others” (p. 4). Both interviewees 1 and 2 seek information from scientifically backed research and from the experiences of others living with T1D, revealing with enthusiasm in their interviews that they found these types of information sources to be the most credible and relevant.

Although both interviewees seek credible sources, they list the Web and Amazon.com over the local public library as places where they seek information. Both respond negatively to the resources provided by their public libraries. Interviewee 1 says the books are “outdated and on type 2 at my library.” Interviewee 2 says “everything I want I can find by Googling. I want the latest research, not an outdated book.” These individuals find traditional libraries to be lacking in up-to-date resources on their disease.

Interviewees 3 and 4 are both males in their mid-thirties residing in the United States. Interviewee 3 has been a member of Glu since 2013 and states he seeks out his information about T1D from various online sources, including the online diabetes research newsletter DiaTribe, blogs, YouTube, the social media personality Diabetic Danica, and Facebook groups. He likes the connection the Glu community gives him, stating, “Glu is pretty awesome as far as online T1D info and support.” This statement reveals that Interviewee 3's interaction with other Glu members goes beyond information-seeking to support-giving behavior, solidifying Glu's presence as a community. Like Interviewee 3, Interviewee 4 is very tech-savvy and is well versed in several social media platforms. Interviewee 4 blogs about living with type 1, creating his own information source. He is also very active on Glu, and has been a member of the community since 2012. He seeks information about T1D from blogs, other online communities such as carbDM, online organizations centered on T1D activism like AYUDA, diabetes research institutes, and Facebook and web forums. He also mentions taking part in the creation of a “type 1 diabetes lingo Wikipedia” that is being developed by other Glu members. Neither Interviewee 3 nor Interviewee 4 lists the library as a

resource for information about managing and coping with T1D. Both seek out information sources created by others living with their disease, preferring the ease and quick response of online sources.

Findings from Flanagan et al. (2013) show that “People tend to find information contributed by similar others to be more credible and are also more likely to indicate that they will act on this information” (p. 10). This is evident in the Glu community; members trust and seek the advice of other members. Interviewees 3 and 4 differ from the first two in that they are invested solely in online- and social-media style sources of information. Although their information-seeking behavior is very social, it is also aligned with the research-based information that Interviewees 1 and 2 value. It is intriguing that all of these types of information sources may be obtained through Glu community interaction, making it the epicenter for people seeking to discover scientific research and share real world experiences about their disease. These interviews also reveal how libraries are lacking as a resource for people living with T1D. All interviewees have negative opinions of the local library when it comes to finding relevant information about T1D and prefer instead the currency of online information sources, including information created by others like them, in the form of blogs, vlogs, Facebook, and social collaboration tools similar to Glu.

Ethical and Legal Issues

Participants in the Glu community are self-aware and determined to access and share the most current information about their chronic disease, which has led the community to connect online. The public nature of information sharing on Glu and OHCs in general makes legal and ethical concerns around issues of privacy and confidentiality inevitable. In order to serve such specialized health communities, LIS professionals must be prepared to handle these challenges. Policies on privacy are confounded as patrons share not only circulation information, but also private medical information via social media sites. Just as it is unethical and illegal to divulge a patron’s personal information, librarians using social media to serve members of this community must also take care to avoid exposing a patron’s private health information. The library, as well as other information communities that make use of social media platforms, must be aware of the potential confidentiality and privacy breeches the very nature of social media creates. Information communities must learn to adapt policies in order to contend with a new set of information ethics.

According to Armstrong et al. (2011), as members become more comfortable in an online community, they begin to share more personal and private information, potentially compromising their privacy and revealing their identity. This is certainly applicable to the online information community of Glu; members ask each other questions about their experiences living with T1D and some users share more information than others. The private medical information members divulge may exist forever on the Internet and be found by anyone, including potential employers, insurance companies, or anyone capable of performing a quick Google search.

Many aspects of the Glu website mimic popular social media websites; members create profiles complete with pictures, join groups, and give out personal information. In doing so, the OHC promotes sharing and creating an open dialogue on all issues related to the chronic disease. However, Glu does not have an established method of protecting community members’ information. Anyone can make a profile and pose as a T1D patient

or as “someone touched by type 1 diabetes” in order to access the personal information of other Glu members. As already indicated, the profiles of Glu members can be found just by Googling their names. This alone creates a plethora of issues surrounding confidentiality and privacy. Like many T1D patients, members of the Glu community often choose not to share with others that they have T1D. Some members have stated that this is because of the misinformation surrounding the disease, while others have said that they do not wish to be judged or identified solely by their medical issue. For example, one member of Glu stated,

I do not want to be seen as diabetic or sick first and a person second. I have type 1 diabetes, type 1 diabetes does not have me. Previous frustrating and ignorant comments from coworkers have led to my decision of no longer disclosing my private medical information with others. (Mardot, personal communication, 2014)

By joining Glu and creating a profile, members potentially give out not only personal information such as date of birth and location, but also private medical information, like how long they have had T1D, what medications they have used, and whether their disease is well managed or spiraling out of their control. For some members of the Glu community, losing their privacy could be devastating. In line with the writings of Michael Zimmer (2013) on social media and information ethics, not only libraries, but all information communities must increase education and outreach to members on the privacy issues that typically accompany the incorporation of the Internet and social media in disease management. Glu and other OHCs are no different, and must be vigilant in protecting members’ privacy and making them aware of the risks of sharing their personal information online.

Special Populations

The T1D community is composed of people of all ages, races and backgrounds, and within this chronic disease community exists a plethora of special populations. One special population of major concern is young, uninsured T1Ds living with limited medical access. Surviving on little to no healthcare besides what they glean from free clinics, emergency rooms, and OHCs like Glu.org, these individuals are at higher levels of risk for chronic stress and poor health management.

In their analysis of research conducted by the Harry B. Helmsley Charitable Trust of 20 young adult T1D patients of low socio-economic status, Pyatak et al. (2013) report that chronic stressors and adverse circumstances make controlling the disease especially difficult for this population. The authors say these “Psychosocial stressors, such as mental health problems, negative family climate and diabetes-related distress, are known to play a significant role in adherence to diabetes self-care and glycemic control . . .” (p. 1140). Other psychological stressors found to affect young adults with T1Ds and no reliable health care include alcohol and drug abuse, low education, incarceration, a history of being abused as a child, learning disabilities, homelessness, and leaving home at a young age. At the time of the study, 80 percent of the participants reported facing at least one of these stressors in their lives.

Young adults living in these circumstances no doubt seek refuge in the free access to health information they find from online diabetes communities like Glu.org. In their conclusion of the research analysis, Pyatak et al. (2013) state that,

The association between psychosocial stressors and glycemic control demonstrated in the present study, and evidence that these stressors are frequently unidentified by care providers, reveals a significant need to address these issues in routine diabetes care, particularly in settings which provide care to underserved populations. (p. 1144)

Just as doctors need to develop methods to treat this significant need, i.e. treating the whole T1D patient and not just the disease, so must librarians. By providing chronic-health communities access to healthcare resources and physical spaces for support groups, and by developing strategies for community outreach, the library has the opportunity to become a beacon for the underserved T1D population.

Technology

Members of Glu rely daily on technology to treat their condition. Members report using smartphone apps, such as BlueLoop, as tools to manage glucose levels and to connect with one another. Members of the community also use a variety of specialized wearable tech to keep an up-to-the-minute, detailed watch on their health and share it with their doctor. These wearable technologies include the insulin pump, which acts as external artificial pancreas, helping to regulate insulin release in the body. The continuous glucose monitor (CGM) acts as a sensor and works in conjunction with the pump, alerting the patient to glucose drops and spikes, helping type 1 diabetics avoid dangerous and embarrassing episodes of low and high blood sugar.

These specialized-health versions of wearable tech help T1D sufferers record glucose levels over a period of time. Otherwise known as life logging, this data is then uploaded to a computer and shared with a doctor in order to find patterns and make adjustments. As Hall (2014) points out, “. . . Collecting, sharing, and analyzing of individual health data can both improve health outcomes for those involved in the data collection and provide those individuals with a level of insight about their health-related behaviors that is not easily achievable through other means” (p. 28). In a consumer health report featured in the *Journal of Engineering & Technology*, author Kris Sangani (2014) points out:

However, the medical sector and the health and fitness fields are divergent in their approach to products and services, mainly due to the fact that the consumer buys their own fitness gadgets while medical devices tend to be procured by healthcare professionals on the behalf of patients. (p. 50)

However for type 1 diabetics, these two sectors are rapidly converging. As medical devices that monitor blood glucose are being adapted to work on smartphones, patients are finding it easy to share this data with loved ones and people in their social network outside of medical professionals. One excellent example of this convergence that has recently been introduced to the market and is being talked about amongst members of the Glu community is the Dexcom SHARE. The Dexcom SHARE is a sensor device that allows T1D patients to closely monitor glucose levels and share the data with others via a smartphone in real time. The Dexcom SHARE can be used anywhere as long as the patient is wearing the device and the person monitoring them has the app on a smartphone. Dexcom's YouTube video suggests the device could be used by parents to monitor their T1D child's glucose levels as they sleep, or by spouses to monitor the

glucose level of their significant other while on a business trip (Dexcom, 2014). Since this device can be used anywhere, it is obvious it is not only tracking pertinent health data but also the location of the user. Although this social sharing of biometric data is promising for type 1 diabetics and their loved ones, it does bring up a host of privacy and legal issues that have yet to be fully explored and understood.

Conclusion

This paper examines the online health community Glu (MyGlu.org), a type 1 diabetes social media site. Type 1 diabetes is a chronic medical condition that requires constant and specialized medical attention. Online health communities like Glu are an important part of maintaining a healthy lifestyle for many members of the T1D community. The Glu community also includes persons living with the chronic medical condition, as well as family members and other supporters touched by the disease who interact with each other and seek out information on T1D by utilizing the Internet, more largely known as the diabetes online community. The motivations and benefits to the community are reciprocal in nature; those affected by T1D benefit from sharing information just as much as receiving information from others like them on a range of topics from medications to social issues surrounding the disease. Members of Glu and the diabetes online community prefer the latest medical research and opinion on their disease and seek out this information by utilizing research databases, medical journals, and type 1 diabetes-focused blogs, vlogs, and other socially-based media platforms; in short, members highly value technology and social information exchange when it comes to managing their chronic medical condition. The T1D community is composed of people of all ages, races, and backgrounds. The economically disadvantaged and underinsured are more likely to suffer from depression, incarceration, and homelessness, especially when living with T1D at a young age (Pyatak et al., 2013). There are ways the local library can reach out to the most vulnerable in this community and make a difference.

Serving the T1D patient community and others like it is a natural fit for libraries seeking to remain relevant by facilitating learning and information sharing for all. A major way the T1D community could be served is by providing space for local support groups to meet. Library staff could also contact and collaborate with local chapters of the American Diabetes Association (ADA), the Juvenile Diabetes Research Foundation (JDRF), and social workers on ways to invite this community into the library and connect them to local services. Librarians should also realize that it is not just students and researchers who need quick and easy access to peer-reviewed and scientific articles; gaining access to current medical research is also highly regarded by T1D patients. Members of communities like Glu do not wish to dig through volumes of irrelevant or outdated books, or to explain their medical history to library staff in order to obtain the information they desire. Library and information science professionals must also realize that diabetes and other chronic diseases are not only a concern of senior citizens; both young and old face the challenges of managing serious health conditions. Serving the information needs of such specialized health communities requires librarians to find a happy medium between discretion, advocacy, understanding, and information accessibility. Although the traditional library may not be able to remedy all of the challenges the T1D community faces, giving their particular information needs thoughtful consideration would be a great start.

References

- American Diabetes Association. (2014). Type 1 diabetes. Retrieved from http://www.diabetes.org/diabetes-basics/type-1/?loc=util-header_type1
- Armstrong, N., Koteyko, N., & Powell, J. (2011). 'Oh dear, should I really be saying that on here?': Issues of identity and authority in an online diabetes community. *Health, 16*(4), 347-365. doi:10.1177/1363459311425514
- Bartlett, Y. K., & Coulson, N. S. (2010). An investigation into the empowerment effects of using online support groups and how this affects health professional/patient communication. *Patient Education & Counseling, 83*, 113-119. doi:10.1016/j.pec.2010.05.029
- Chen, A. T. (2012). Exploring online support spaces: Using cluster analysis to examine breast cancer, diabetes and fibromyalgia support groups. *Patient Education and Counseling, 87*, 250-257. doi:10.1016/j.pec.2011.08.017
- Collazo-Clavell, M., Davidson, N., & Moreland, P. (2014, August 2). Diseases and conditions: Type 1 diabetes. Retrieved from <http://www.mayoclinic.org/diseases-conditions/type-1-diabetes/basics/causes/con-20019573>
- Dexcom. (2014, October 20). Dexcom SHARE [Video file]. Retrieved from <https://www.youtube.com/watch?v=fFBvR9UtOCU>
- Fisher, K. E., Durrance, J., & Unruh, K. T. (2003). Information communities: Characteristics gleaned from studies of three online networks. *Journal of the Association for Information Science and Technology*. Retrieved from <http://ibec.ischool.washington.edu/static/pubs/asist2003.pdf>
- Flanagin, A. J., Hocevar, K. P., & Samahito, S. N. (2013). Connecting with the user-generated web: How group identification impacts online information sharing and evaluation. *Information, Communication & Society, 1*-12. doi:10.1080/1369118X.2013.808361
- Gilbert, K., Dodson, S., Gill, M., & McKenzie, R. (2012). Online communities are valued by people with type 1 diabetes for peer support: How well do health professionals understand this? *Diabetes Spectrum, 25*(3), 180-190.
- Glu. (2013a). Frequently asked questions. Retrieved from <https://myglu.org/>
- Glu. (2013b). About us. Retrieved from <https://myglu.org>
- Hall, T. S. (2014). The quantified self movement: Legal challenges and benefits of personal biometric data tracking. *Akron Intellectual Property Journal, 7*(1), 27-37.
- Ho, Y., O'Connor, B. H., & Mulvaney, S. A. (2014). Features of online health communities for adolescents with type 1 diabetes. *Western Journal of Nursing Research, 36*(9), 1183-1198. doi:10.1177/0193945913520414
- Ilioudi, S., Lazakidou, A., Glezakos, N., & Tsironi, M. (2012). Health-related virtual

- communities and social networking services. In A. A. Lazakidou (Series Ed.), *Virtual Communities, Social Networks and Collaboration* (pp. 1-13). doi:10.1007/978-1-4614-3634-8_1
- Massimi, M., Bender, J., Witteman, H. O., Ahmed, O. H. (2014, February). Life transitions and online health communities: Reflecting on adoption, use, and disengagement, presented at the Computer-Supported Cooperative Work and Social Computing Conference, Baltimore, MD. 2014. doi:10.1145/2531602.2531622
- Newman, M. W., Lauterbach, D., Munson, S. A., Resnick, P., & Morris, M. E. (2011, March). "It's not that I don't have problems, I'm just not putting them on Facebook": Challenges and opportunities in using online social networks for health, presented at the meeting of the Computer Supported Cooperative Work, Hangzhou, China. 2011.
- Oh, H. J., & Lee, B. (2012). The effects of computer-mediated social support in online communities on patient empowerment and doctor-patient communication. *Health Communication, 27*, 30-41. doi:10.1080/10410236.2011.567449
- Pyatak, E. A., Sequeira, P., Peters, A. L., Montoya, L., & Weigensberg, M. J. (2013). Disclosure of psychological stressors affecting diabetes care among uninsured young adults with type 1 diabetes. *Diabetic Medicine, 30*(9), 1140-1144. doi:10.1111/dme.12248
- Sangani, K. (2014). Vice versa. *Engineering & Technology, 9*(5), 50-53.
- Zimmer, M. (2013). Assessing the treatment of patron privacy in library 2.0 literature. *Information Technology & Libraries, 32*(2). doi:10.6017/ital.v3 2i2.3420