

COMMENTARY

Diabetes and social media: a prescription for patient engagement



Manny Hernandez*

“...these anecdotal examples support the notion that peer support via social media benefits some adults living with diabetes.”

Social media permeates through every aspect of society, diabetes included. Online communities, blogs and Twitter chats are among the resources that allow patients to connect with their peers, getting access to support and information, empowering them to become better advocates on their behalf and on behalf of others. By better understanding this trend, medical professionals can point their patients in the right direction and have an open dialog with them about social media as a resource to support their diabetes management.

Social networks are hardly a novelty any more. Even our parents who used to shy away from Facebook now flock to the popular social network to stay connected with their children and grandchildren. However, this article is not about Facebook. This commentary will highlight diabetes social networks and blogs, social media websites for people with diabetes and their loved ones.

“...one in four adults (24%) says that they turned to others who have the same health condition during their last bout with illness.”

According to the Pew Internet Project [101].

Online communities such as TuDiabetes, Diabetes Daily and Children With Diabetes; blogs such as DiabetesMine and Six Until Me; and the weekly #DSMA Twitter chat are some of the social media outlets that facilitate connections between people affected by diabetes.

Benefits of diabetes & social media

Connecting with peers and having an open dialog about mutual experiences with this chronic condition energizes people in impressive ways. People start feeling understood and engaging with their condition. There are cases such as a retired high-school principal with Type 2 diabetes who spent years in denial. Joining TuDiabetes gave him a sense of belonging and furnished him with new tools and ideas to have an informed conversation with his physician, helping him lower his HbA1c from 9.5 to 5.9%.

We have also seen cases such as a female patient who grew up with Type 1 diabetes and always looked forward to having children, but struggled with achieving the tight control recommended for a safe pregnancy. Connecting online with other women who had had successful pregnancies allowed her



*1962 University Avenue, Berkeley, CA, USA; Tel.: +1 510 898 1301; manny@diabeteshf.org

to learn new ways to think about diet and other areas of her life affected by diabetes, including pump therapy and continuous glucose monitoring. As a result of this, the patient now has two children that remind her daily of the lessons she learned from her peers.

Patients that become empowered by connections made through social media can become better advocates for themselves. A great deal of awareness surrounding latent autoimmune diabetes of adulthood as a plausible diabetes diagnosis among adults has largely resulted from patient advocacy efforts. For primary care physicians who may not be familiar with this autoimmune form of the condition that occurs later in life, informed patients can be a precious asset that can save frustration, time and resources, both for the doctor and for the patient.

Furthermore, social media has made it possible for patients to go beyond helping themselves, allowing them to have a lasting impact on the lives of others. An example of this is the Artificial Pancreas project petition driven by Juvenile Diabetes Research Foundation (JDRF), which got more than 100,000 people to support this initiative.

While further well-designed evaluations of the effectiveness and impact of social media are needed to support firm recommendations [1], these anecdotal examples support the notion that peer support via social media benefits some adults living with diabetes. Clearly, peers can provide the kind of ongoing support that is needed for sustained self-management of diabetes [2].

“Peer-to-peer healthcare is a way for people to do what they have always done – lend a hand, lend an ear, lend advice – but at internet speed and at internet scale.”

As Pew Internet’s Susannah Fox perfectly summarizes [102].

What can physicians do?

With the growing constraints of most health-care systems around the world, physicians are under increased pressure; having to deal with more patients and complete more paperwork in the same amount of time. In the end, the average person with diabetes spends no more than 0.1% of their time in the course of an entire year discussing health matters with a medical professional, and we are collectively losing the battle on diabetes.

Patients do not leave their diabetes behind at any point in their lives, diabetes is a self-management condition, and connected and engaged patients can become empowered with life-changing information and support, as discussed earlier. In this scenario, the titanic work of physicians can be handsomely complemented by having them recommend that their patients start taking part in social media to help them with their diabetes management. As a result, patients get at least two critical things physicians cannot normally offer: the perspective from the point of view of another patient, and an almost unlimited amount of time to listen and share experiences.

When talking about diabetes and social media, one of the main concerns I hear among medical professionals is that it can also be a source of misinformation. While this is true and people should not treat online information as medical advice, before you give up on social media and its value, consider first that a large number of your patients (young and old), are already using it: as of October 2012, more than a billion people are on Facebook [103], and 56% of internet users 50 years old or older are using Facebook [104].

Becoming familiarized with trustworthy websites to recommend them to patients as resources where they can connect with their peers and obtain 24/7 support is one of the most valuable things a medical professional can do to empower patients beyond the time they spend together.

To help separate ‘the wheat from the chaff’ in diabetes social media, it helps to read a website’s disclosures, the degree to which it agrees with clinical standards, how accessible and readable its privacy policies are, and what controls on sharing data it offers [105]. Of course, sites certified by the Health On The Net Foundation already abide to a code of conduct with the goal to promote useful and reliable online health information, and its appropriate and efficient use [106]. It also helps to ask patients to share any websites they may be reading or participating in, to help patients sort fact from fiction.

Behind the most successful social media outlets for people affected by diabetes has been an inspired patient advocate: someone who was diagnosed with diabetes or who had a loved one diagnosed, who is determined to make a difference in the lives of others. In an effort to empower some of these efforts, the Diabetes Hands Foundation (CA, USA) we created a

program called Diabetes Advocates, which can serve as a starting point for physicians wanting to recommend social media to their patients. Nearly 60% of the member sites in this program are either Health On the Net Foundation Code certified or in the process of getting their certification.

Future perspective

By the end of the decade, more than 500 million people around the world are expected to be diagnosed with diabetes. Technology to support patients and physicians will emerge and evolve. For instance, with the unparalleled worldwide adoption of smartphones we are sure to see more and more mobile apps. Technology will power

connections and empower patients, allowing individuals with diabetes to connect with their peers, making sure that nobody with diabetes ever feels alone again.

Financial & competing interests disclosure

M Hernandez heads the Diabetes Hands Foundation, a nonprofit organization that seeks to understand, connect and energize the millions of people living with diabetes. The author has no other relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript apart from those disclosed.

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References

- 1 Dale JR, Williams SM, Bowyer V. What is the effect of peer support on diabetes outcomes in adults? A systematic review. *Diabet. Med.* 29(11), 1361–1377 (2012).
- 2 Fisher EB, Boothroyd RI, Coufal MM *et al.* Peer support for self-management of diabetes improved outcomes in international settings. *Health Aff. (Millwood)* 31(1), 130–139 (2012).

■ Websites

- 101 Fox S, Duggan M. Health Online 2013. http://pewinternet.org/-/media/Files/Reports/PIP_HealthOnline.pdf
- 102 Fox S. Medicine 2.0: peer-to-peer healthcare. www.pewinternet.org/Reports/2011/Medicine-20/Part-1.aspx
- 103 Ortutay B. Facebook tops 1 billion users. www.usatoday.com/story/tech/2012/10/04/facebook-tops-1-billion-users/1612613/
- 104 Rainie L, Brenner J, Purcell K. Photos and videos as social currency online. <http://pewinternet.org/Reports/2012/Online-Pictures.aspx#1>
- 105 Warshaw H, Edelman D, Tenderich M, Hernandez M. THE DOC (Diabetes Online Community): what the heck is going on? www.slideshare.net/tudiabetes/the-doc-what-the-heck-is-going-on
- 106 Health On the Net Foundation (HON). HONcode: principles – quality and trustworthy health information. www.hon.ch/HONcode/Conduct.html