In Brief

This article addresses modern patients' insatiable need for information as they make daily choices in managing diabetes. It introduces the resources available to diabetes patients and caregivers against the backdrop of the limitations medical practices face in meeting patients' information and support needs. Social media are described, along with ways in which health care providers might leverage digital technology to better support their patients. The author describes trends and studies that suggest how social media might be used in the future not only to meet patients' needs, but also to streamline clinical workflow.

Power and Pitfalls of Social Media in Diabetes Care

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Health care providers (HCPs) cannot be accessible 24 × 7 × 365 to answer endless patient questions, nor would they want to be. As a result, patients turn elsewhere for answers, including to communication sources collectively known as "social media" (e.g., Facebook, Twitter, Internet forums, blogs, and podcasts).

Although many HCPs believe these forms of communication may be helpful, social media's potential for providing misinformation and questionable patient-to-patient medical advice represents a risk to patients and can introduce inefficiencies in clinical workflow. Rather than fall victim to the pitfalls of social media, HCPs can leverage these technologies to ensure their participation in meeting their patients' education and support needs. This article offers guidance to help diabetes HCPs understand the scope of social media, how people use them as a tool for managing diabetes, and how best to harness their power to the benefit of both patients and the clinical practice.

When HCPs are not available to listen to patients or provide answers or general support at the moment they are needed, patients and their lay caregivers can easily find themselves adrift on a stormy sea of "information" offered by friends, family, coworkers, and online sources. The quality of information available through social media can vary greatly, not unlike that gleaned through a casual conversation at the office water cooler. However, information in the digital forum has the potential to extend to exponentially more people, may lose its original context, and has a possibly infinite lifespan, making it all the more potentially dangerous. Still, many people believe that, "If it's on the Internet, it must be true."

The Federation of State Medical Boards' 2012 report "Model Policy Guidelines for the Appropriate Use of Social Media and Social Networking in Medical Practice"[1] defined "social media" as "electronic communication through which users create online communities to share information, ideas, personal messages, and other content." That definition has been adopted for the purposes of this article.

It is important to understand the extent to which social media contribute to patients' communications related to diabetes care. This can range from someone sharing something they read online with a patient, real-time messaging about diabetes between two people on their smartphones, online forum discussions involving many people over an extended period of time, and countless other situations. And the quality of information can vary among all of these situations. For example, when the author sought input for this article from members of the tudiabetes.org online diabetes community of > 25,000 members, several members pointed out differences between their online community and what one might find when looking for similar communications at Internet sites such as Facebook or Twitter. One difference they noted is the self-

policing culture that has evolved within their community to help protect people from misinformation.

Today's patients are subject to numerous influences through social media outlets. Many people with diabetes have developed their skills and regimen beyond what has been prescribed by their HCP, and these do-it-yourselfers often enjoy sharing their experiences with others. In many cases, knowledgeable patient advocates in diabetes online communities (childrenwithdiabetes.com and diabeticconnect.com are additional examples) share their frustration with providers who they say are not readily available to patients or lack the experience to provide high-quality, patient-specific guidance. Pharmaceutical and medical device companies who engage in direct-to-patient communication via television, Internet, direct mail, and other outlets also influence patients without their providers' involvement.

HCPs have several options related to their involvement in social media with regard to patient care:

- Ignore them, and hope they will go away
- Invite your patients to "like" you on Facebook
- Spend a lot of time and money becoming a social media expert, and create your own media empire
- Evaluate a reasonable number of potential resources for information and refer your patients
- Gradually expand your practice resources in a social-media manner, starting with patient education and support

Notice that spending more time with patients during their infrequent office visits is not one of the options offered. Although office visits can be an effective method of patient care, they do little to address patient needs between office visits. Extended time during office visits can often be a highly inefficient use of scarce resources. Self-directed online research is a more accessible resource.

Patients at highest risk of asking questions and receiving misinformation may be those who are newly diagnosed, given their lack of experience and hunger for more information. Newly diagnosed patients often fail to understand that what works for one person may not be appropriate for another. Many also fail to call the clinic as needed because they do not want to bother their doctor with "silly" questions. Social media offer a wealth of information, but it is the appropriate filtering and application of this information that offers a promising solution to this age-old challenge.

Close the Gap: Identify Unqualified Medical Advice

At a minimum, trained medical professionals have a responsibility to identify the issuance of medical advice to patients by unqualified individuals or anonymous resources and ensure patients' safety. Strategies for minimizing risks inherent in social media include:

- Accepting that many patients are going to seek medical advice via social media
- To the extent that your practice can, filling the gap by meeting patients' needs for information and support
- Training patients to know how to reach your medical advice line
- Issuing guidelines to patients regarding medical information from social media sources
- Demanding that medical associations take the lead
- Offering to participate formally in social media forums
- Aligning with peers who already have an online presence
- Creating an education resource base from medical advice routinely issued by your practice
- Engaging patients by collecting e-mail and phone numbers for education purposes
- Determining in which forums or support groups patients participate
- Evaluating and aligning with a few social media outlets that meet your standards

Fill the Gap: Be the Resource

The drive behind the rise in the prevalence of social media is without doubt a powerful indicator that patients desire to acknowledge their diabetes. However, time spent on social media may be spent more productively elsewhere. Given that one of the most common excuses for lack of exercise is lack of time, it is interesting to note that the average amount of time spent on diabetes-related social media websites (typically done while sitting) can be several hours per week. Harnessing social media can help HCPs provide patients with the right answers in a timely manner, thus helping them minimize their sedentary time online and to lead a more active life.

Pitfalls of Social Media

In the setting of casual social media connections, it is quite possible that patients seeking advice online may not share or understand their comorbidities. Likewise, patients offering advice to others may not be aware of their recipients' complete medical history.

The content on social media sites often is controlled by a very small percentage of their stated membership; most people only monitor such sites and never post anything. There are supportive communications, but also petty human behaviors such as bullying when one person's beliefs are challenged by other members. For patients seeking support or motivation, such negative experiences, even if merely monitoring from the background, can result in even greater feelings of isolation regarding their condition.

Health On the Net is an initiative that was launched in 1995 as a way to let people know that certain standards have been followed to make sure that information provided via a website complies with generally accepted principles. However, this initiative is limited to managed content on static websites and does not encompass, for example, "tweets" (a brief message via a popular online public messaging site at www.twitter.com) from some average Joe about the "best" way to dose insulin. More recently, Google has joined the effort, seeking to extend the vetting of content and online publishers via an initiative called Google Co-op.[2] There are also conferences to promote discussion of Internet issues and solutions within the professional community (i.e., the Doctors 2.0 & You conference held in Paris every year since 2011 [http://doctors20.com]). Such initiatives are encouraging first steps toward the eventual establishment of industry best practices. However, that day is not yet near, and today's HCPs will likely need to make decisions in this area on their own.

Power of Social Media

Not surprisingly, a quick search of the website pubmed.gov using the terms "social media," "evidence base," and "diabetes" results in a notice of "no items found." Replacing "social media" with "digital media," "direct

mail," or "post card" returns the same result. Removing the reference to diabetes returns only a few results. In one study of teen sexual behaviors involving social media and other forms of digital communication,[3] modest gains were made in promoting teen abstinence. However, this study was of short duration and the authors recommended longer-term studies.

Otherwise, the evidence base for social media in any context appears to be woefully lacking and leaves HCPs with only a few guidelines for what not to do. In a study by Visser et al.,[4] a helpful checklist is provided to assist providers in assessing their own activities and social media presence. Although helpful, this emphasis on what not to do without the counterbalance of actual studies describing effective positive actions leaves HCPs in fear of these relatively recent communication channels for engaging patients in diabetes care.

Tools for Engaging With Patients

For those readers who may not be familiar with the differences among the most popular social media options, I have provided examples describing, in a lighthearted way, several of the social media options available to HCPs (Figure 1) and how they might be utilized.[1]

Following is a description of my current toolset for my own social media projects. These tools were selected after evaluating many of the available options. Innovations and upgrades are constantly being made available, so this example may not be ideal for every HCP's long-term use. However, it does provide a simple starting point.

Of course, countless medical practices and patient websites offer information to visitors, as well as the potential for visitors to post comments. This type of forum, commonly known as a "blog" (short for "web log") can be easily set up using various available tools. One of the easiest, wordpress.com, is a low-cost path for practices that want to advance their online presence.

Organizational tools

Tools such as Seesmic and Hootsuite allow authors of online social media to write once and publish to any number of online outlets with ease. One can write a brief educational post using a tool such as Hootsuite, select specific online outlets, and publish the post on all of them with a single mouse click.

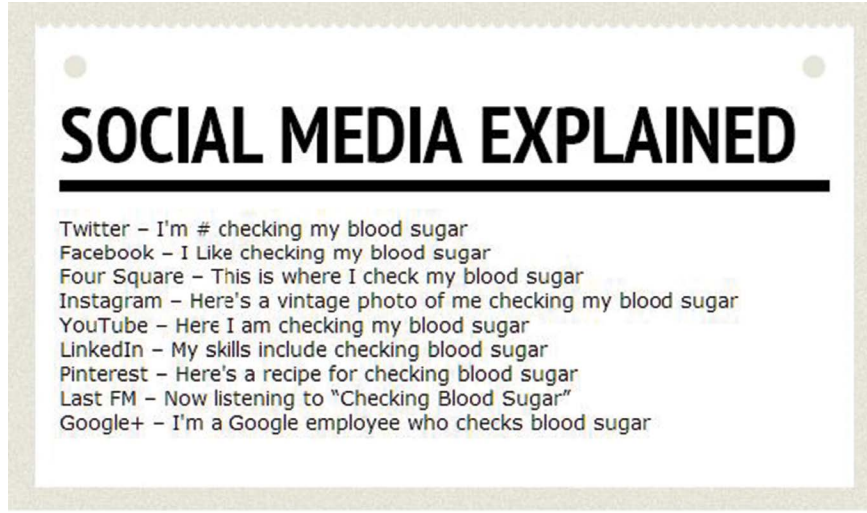

Figure 1. A humorous look at diabetes in the social media.

Efficiency tools

These productivity tools, including Seesmic and Hootsuite, can be extremely helpful, offering, for example, the ability to schedule a series of posts for specific times in the future.

Tools for curating your education library

As one's online presence grows in terms of the content published and the patients who read it, it may become helpful to locate the entire collection in one centralized site. One of the most valuable facets of Internet technology is the ability it affords people to search and retrieve previously posted information. This certainly beats the common practice of repeating advice or re-writing e-mails on the same topic to patients. Instead, previously posted content becomes a resource library with a unique Internet address. HCPs seeking to fully leverage their online content may consider setting up and referring patients to a unique web address (e.g., http://mypractice.com/guidelines/highbloodsugarchecklist) to increase effectiveness and clinical workflow.

Tools for monitoring utilization of online offerings

HCPs who want to find out how often their posts are accessed might consider using a tool such as Bitly (https://bitly.com), a bookmarking and tracking service that offers usage statistics. Bitly users can shorten their Internet URL address for easy manual entry (e.g., the Bitly address http://j.mp/mphbsc takes users to the same Internet site as http://mypractice.com/guidelines/highbloodsugarchecklist. Bitly also tracks how often and when each site is accessed, providing detailed statistics that allow content providers to focus on their resources that are used most frequently. Bitly links can also track how often patients access mainstream resources such as the homepage of the American Diabetes Association (http://j.mp/149mQKn) or the Juvenile Diabetes Research Foundation (http://j.mp/ZfBNmm).

Never Fear: Start Exploring Now

Although expert-level instruction on using social media is beyond the scope of this article, the information provided above should convince HCPs that these powerful tools are low in cost and highly accessible and have the potential to help medical practices identify, close, and fill gaps in their patients' information resources. Still wary? Consider asking the nearest 13-year-old for a hands-on tutorial. It's that easy.

Future of Social Media in Diabetes Care

As part of the federal government's staged implementation of "meaningful use" measures for electronic health records (EHRs) (see the article by Teresa L. Pearson, MS, RN, CDE, FAADE, in this issue for a more complete discussion of this [p. 221]), medical practices engaged in achieving Stage 2 of Meaningful Use will be required in 2014 to have at least 5% of their patients enrolled and actively participating in secure digital communications (i.e., patient portals).[5] Rather than focusing on 5%, why not aim for 50%? As a strategy, this would allow

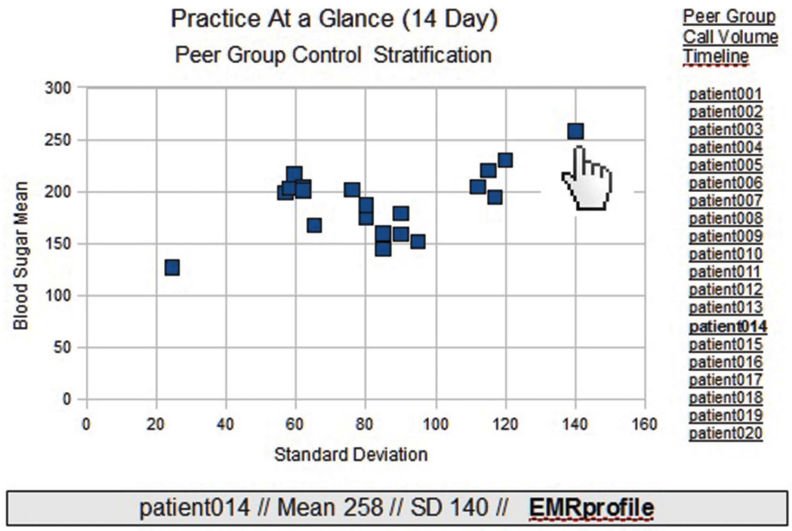

Figure 2. Triage plot for Practice at a Glance, an original system and report designed and implemented by the author and his firm, Diabetech, in support of a feasibility study of real-time remote monitoring of children and families with type 1 diabetes. Adapted from ref. 6.

practices to focus on a serious time-intensive facet of their operations and offer specialized and useful services to a large number of patients. For many practices, the combination of patients with a diabetes diagnosis and those at risk for progressing to a diabetes diagnosis easily exceeds 5% of the total patient population.

Leveraging the competitive side of human nature for diabetes care can generate great interest from patients. A clinical study conducted from December 2002 to May 2003 and presented at the third annual Diabetes Technology Meeting of the Diabetes Technology Society serves as an example (Figure 2).[6] The presented poster included peer-group stratification and visually compelling blood glucose analysis. Figure 2 shows all patients in the study stratified by their most recent 14-day self-reported blood glucose average along the vertical axis and the corresponding standard deviation along the horizontal axis.

In the figure, one can see that patient 014 "led the pack" in terms of uncontrolled blood glucose. If we were to add to this information that fact that this patient was newly diagnosed, one could easily imagine the stress on the patient's family and the patient's relative risk of a late-night emergency department visit for diabetic ketoacidosis. Being mindful of the liability ramifications that unbridled access to such data represents, the medical practice could make excellent use of this information by integrating it as a feature of social media for educational purposes.

As part of the enrollment process in this study, the researchers facilitated communication among the anonymous participants. All participants were invited to view these data graphs via a standard Internet web browser.

This graph represents one of the earliest examples in which the Internet provided the ability to aggregate data into a "practice-at-a-glance" tool, which can be easily imagined as a feature of today's EHRs. But when it was used directly by patients as a social-influence tool, patients reported great satisfaction in knowing they were not alone in their struggles to manage their diabetes. Furthermore, patients exchanged encouraging words of support prompted by temporary swings in individual participants' blood glucose control. Participants also reported validation of their struggle to control their blood glucose when the one participant with maturity-onset diabetes of the young (shown in Figure 2 and represented consistently throughout the study as the patient in sole possession of the lower left quadrant) struggled with temporarily poor glycemic control because of an acute illness. There remains much to learn about the social aspects of diabetes management when catalyzed by peer-group data visualizations.

Conclusion

Social media can be powerful new channels for leveraging peer influence in diabetes self-care. Even in the short term, ignoring this rich and diverse well of information will be a disservice to patients. With minimal investments of time and little to no direct costs, HCPs can familiarize themselves with a few available social media outlets and demonstrate to patients that their providers take an active interest in their well-being and are committed to keeping up with the times. In the longer term, engaging patients via social media in the care of diabetes will offer communication efficiencies that promise to deliver significant return on any investments of time and money.

Acknowledgments

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References

[1]Federation of State Medical Boards: Model policy guidelines for the appropriate use of social media and social networking in medical practice. Available from http://fsmb.org/pdf/pub-social-media-guidelines.pdf. Accessed 4 September 2013

[2]Google Co-op: http://www.hon.ch/Project/GoogleCoop/Projectgoogle_demo.htm

[3]Guse K, Levine D, Martins S, Lira A, Gaarde J, Westmorland W, Gilliam M: Interventions using new digital media to improve adolescent sexual health: a systematic review. *J Adolesc Health* 51:535–543, 2012

[4]Visser BJ, Huiskes F, Korevaar DA: A social media self-evaluation checklist for medical practitioners. *Indian J Med Ethics* 9:245–248, 2012

[5]Centers for Medicare and Medicaid Services: Stage 2 overview tip sheet. Available from http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/Downloads/Stage2Overview_Tipsheet.pdf. Accessed 30 September 2013

[6]Ponder S, McMahon K: Wireless-enabled proactive diabetes management [abstract]. *Diabetes Technol Ther* 6:265, 2004 (doi:10.1089/152091504773731429)

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