Social Media Made Easy: Guiding Patients to Credible Online Health Information and Engagement Resources

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Within the changing dynamic of health care, health care professionals (HCPs) are no longer the sole sources of health information. Recent estimates suggest that 83% of Internet users with chronic conditions such as diabetes go online to look for health information.[1] People with diabetes seek online information about the condition, treatment options, practical strategies and tools for managing diabetes in their daily lives, scientific breakthroughs, and advocacy efforts.[2] Yet, a Google search for "diabetes" returns 290 million results. A search for "diabetes online support" yields close to 36 million results. This can be overwhelming for anyone.

Some HCPs assist with this information overload by filtering and narrowing down online resources and search results for their patients. SurroundHealth, an online learning community for nonphysician HCPs, recently surveyed its members about the use of educational technology in health care. Many respondents reported that they used time during patient interactions to refer patients to online resources. Eighty-two percent of HCPs in private practice reported having referred patients to specific online resources, compared to 60% of HCPs in outpatient clinics and 52% of HCPs in hospital settings.

The HCPs who made referrals intended to help patients overcome common online obstacles such as difficulty distinguishing between high-quality information and material that is out of date, inaccurate, or overly promotional.[3] Connecting patients to credible online health information during office visits can facilitate more appropriate use of health care resources, shorter clinical encounters, more patient-centered decision-making, and, in some cases, reduced barriers to treatment adherence.[4,5]

This article explains how online health information and engagement resources are integrated into patients' overall health care experiences. In addition, it addresses common HCP concerns about patients accessing online resources and will outline steps that busy professionals can take to help connect patients to appropriate online resources.

Online Health Information Resources Versus Online Health Engagement Resources

Online health information resources push information out to the patient, whereas online health engagement resources promote the sharing of information, as well as support and interaction among patients.

Within an online health information resource, the information flows in one direction—from the content author to people with diabetes. The content reflects the perspectives and priorities of the author or author's organization. The author determines what information to share and when and how to share it. Typically conveyed in an objective manner, the information is usually vetted for factual accuracy before publication.

Examples of online health information resources for people with diabetes include Web sites of the American Diabetes Association (ADA; www.diabetes.org), the National Diabetes Education Program (www.ndep.nih.gov), and the Centers for Disease Control and Prevention's Diabetes Public Health Resource (www.cdc.gov/diabetes). In addition, people with diabetes can find credible health information resources via online learning centers affiliated with medical centers such as the Joslin Diabetes Center (www. joslin.org).

In contrast, online health engagement resources are social-networking tools and platforms (e.g., blogs, Twitter, Facebook, YouTube, and other online community sites) that allow active, two-way sharing of information (Table 1). Created by participants or community members, content often focuses on the real-life challenges of living with a particular disease or condition and offers emotional support, encouragement, coping, and problem-solving. People with diabetes often determine for themselves which specific health engagement resources are most useful and credible based on their life situation and learning needs. The information in health engagement resources is not guaranteed to be vetted for factual accuracy and may

Table 1. Comparison of Social Networking Tools and Platforms		
Types of Platforms	**Examples of Usage for Health Engagement**	**Key Benefits to Platform**
Social networks (e.g., Facebook)	1. Patients share information with family and friends. 2. Patients join groups related to conditions and diseases. 3. Patients can "like" pages from organizations and causes and can access education and other resources shared by the organization.	Patients can determine the privacy of each piece of content that they post to their network and go back and change the privacy level if they change their mind about a post.
Microblogging (e.g., Twitter)	1. Patients share information with family and friends and potentially a larger audience of followers. 2. Patients can easily search using "hashtags," or key terms, to find resources or ongoing conversations about health topics. 3. Patients can find, join, or create mini-communities. 4. Patients can join scheduled chats about different health care topics. 5. Patients can get feedback and information by asking questions to their followers, which could include health care professionals or fellow patients.	Patients can find new communities and other patients regardless of their geographical location. Feedback and engagement is not reliant on preexisting networks; networks are easily expanded.
Blogs	1. Patients share information with family and friends and/or a potentially larger audience of followers or people who find their blogs via an Internet search. 2. Patients can embed content from other platforms (e.g., video) and use a variety of tools to tell their story.	Patients are not limited by space restraints (such as on Twitter) in sharing their thoughts or experiences.
Video platforms (e.g., YouTube)	1. Patients can chronicle their experience and share information via video. 2. As the #2 search engine after Google, YouTube offers thousands of health-related videos that patients can interact with and learn from, whether personal videos or organizations' educational videos.	Visual storytelling is compelling and engaging and can be used to demonstrate medical devices or other tools.
Health-specific social networks	1. Patients can join existing health-specific communities for support and resources. 2. Many communities have their own curated list of resources and recommendations for members and often provide formal or informal guidance from community members.	Content shared in health-specific networks is usually not shared with friends, family members, or coworkers unless it is cross-shared to another platform; this often gives patients a protected place to discuss and engage on health topics rather than with their other existing social networks.

reflect an individual's opinion or experiences.

Examples of online health engagement resources for people with diabetes include TuDiabetes. org (www.tudiabetes.org), Diabetes Social Media Advocacy (DSMA) (www.diabetessocmed.com), Children With Diabetes (www. childrenwithdiabetes.com), and You Can Do This Project (www.youcan-dothisproject.com). In general, the

Table 2. Comparison of Health Information and Health Engagement Resources		
Characteristic	**Health Information Resources**	**Health Engagement Resources**
Flow of information	One way: pushed out from content author to people with diabetes	Two way: created by participants (people with diabetes, family, friends, and HCPs) using social media tools and platforms such as Twitter and YouTube
Tone	Objective, factual	Experiential, collaborative, and motivational
Accuracy	Content typically fact-checked before published	Informal self-policing of shared content among participants; most useful and credible resources gain validation and trust
Examples	www.diabetes.org www.ndep.nih.gov www.cdc.gov/diabetes www.joslin.org	www.tudiabetes.org www.diabetessocmed.com www.childrenwithdiabetes.com www.youcandothisproject.com

goal of health engagement resources is not to undermine the professional-patient therapeutic alliance or replace medical recommendations, but rather to serve as a source of inspiration, offer motivation and encouragement, and provide a sense of community.

Limited formal evidence exists of the effect of patients' involvement in social media on their overall health. However, research is underway to determine whether participation in a controlled social network of HCPs, patients, friends, and family members has a positive effect on knowledge, attitudes, and diabetes self-care management.[6] Although providers seek evidence to support the use of social media in improving diabetes care, people with diabetes view social media as tools to facilitate connecting with others, not as an intervention or a treatment approach.

Well-known blogger Kerri Sparling, who has type 1 diabetes, commented in a recent column titled "Proof Is in the People,"[7] on HCPs' interest in evidence: "Through connecting online, and in person, people living with diabetes have concrete proof that they are not alone, and that there is health worth fighting for, even after a diabetes diagnosis.

Social media . . . shows people that there isn't such a thing as a 'perfect diabetic,' but there can be an educated and determined one. It lets people know they aren't alone in the ebb and flow of their diabetes management. It doesn't encourage people to wallow in their troubles, but serves to inspire them to do the best they can, and to seek out the best healthcare they can find, both at home and in their doctor's offices."

Although the characteristics of health information resources differ from those of health engagement resources (Table 2), many people with diabetes consider both to be part of their overall online experience (Figure 1). In combination, online health information and health engagement resources represent informal learning and support that can complement the more formal information and education that
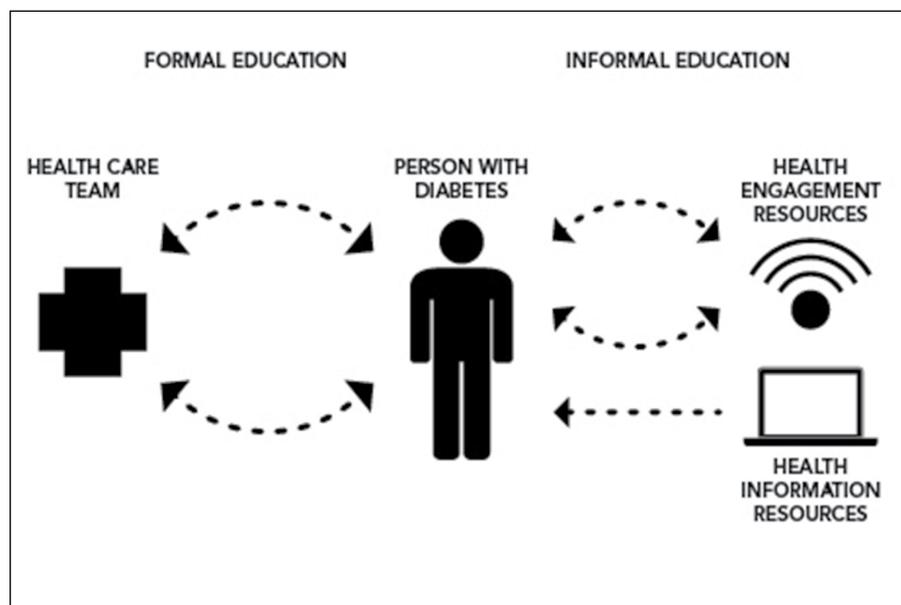

Figure 1. Online health information and health engagement resources represent informal education and support that can complement the more formal education people with diabetes receive from their health care team during office visits.

people with diabetes receive from their HCPs.

These resources are also there for HCPs' use. By going online and becoming acquainted with the different resources, HCPs may gain a better perspective on how their patients experience and learn from such sites. However, even with a deeper understanding of the value of online resources for patients, HCPs may struggle with concerns about protection of patient privacy, their professional responsibility, and the time constraints involved in staying up to date on available resources.

Overcoming Concerns About Privacy and Time

HCPs may hesitate to learn about or participate in social media because of concerns related to the Health Insurance Portability and Accountability Act (HIPAA) and uncertainty about how much to engage with people (possibly patients) online. HIPAA protects patients' privacy by limiting the ways in which their information is shared with others. Patients can choose to share or engage online and provide personal health information, whether about their care and treatment, health care decisions, or details of their patient-professional interactions. HCPs' reading of content that patients chose to share online does not violate HIPAA. However, commenting in a public setting to an individual patient without the patient's signed consent may be considered a HIPAA violation or cause concern that the patient's privacy is not being protected or respected.[8] Even if an HCP has a signed patient consent form, when commenting within a public viewable health engagement resource, the professional should provide only general health information and avoid specific, individualized medical advice. Privacy-protected e-mail is the best tool for direct online communication

about medical care with individual patients.

Lack of time is another deterrent to embracing social media for busy HCPs. In addition to more traditional avenues of continuing education (e.g., medical meetings, symposia, and peer-reviewed journals), HCPs may benefit from supplementing their education with social learning and curation. Curation is the process of evaluating a range of available resources and identifying specific ones that are most appropriate for patients' needs. Like a museum curator selecting pieces of art to include in a display, HPCs can identify and select online resources to share with their patients. Ultimately, the curated resources that professionals share with their patients can be an effective strategy to both enhance direct-to-patient education and save time during in-office education. In addition, posted patient experiences within the resources can help HCPs themselves learn about patients' challenges and insights related to new treatments and technologies.

Patients' Perceptions of HCPs' Involvement in Social Media

Because of the availability of social media tools, people with diabetes can now congregate and interact with each other online without restrictions of geographical location. Thus, online networking and engagement by people with diabetes is collectively referred to as "the diabetes online community." This online community also includes friends, family, and HCPs who work with people with diabetes.

DSMA holds weekly Twitter chats, known as #DSMA, for people with diabetes. During the 20 June 2012 chat, participants were asked to comment about whether having HCPs using social media was valuable. Responses included, "Yes, it will help them learn more about the

24/7 aspects to living with diabetes," "Yes, but I worry about 'big brother medical care'," and "Yes, to connect on a more human level, but no lecturing/knowing what's best." Overall, the #DSMA community consensus appeared to be that participation by HCPs in social media would be valuable and could help HCPs further their understanding of the complex issues that people with diabetes must deal with daily.[9]

Building the Bridge From Office Visit to Online Interaction: Time-Saving Approaches

Helping patients access online health engagement resources does not have to be a time-consuming endeavor, and professionals do not have to actively use all social media platforms and tools. Professionals can use the steps to curate credible resource suggestions for their patients.

1. Solicit and review recommendations. Ask staff members and patients to share their favorite online health information and engagement resources for diabetes. A listing of many health engagement resources can also be found at the Diabetes Advocates Web site (www.diabetes advocates.org; click on the tab for Members and Resources). Diabetes Advocates identifies a number of health engagement resources specifically for people with type 1 or type 2 diabetes, for parents of children with diabetes, and for Spanish-speaking people with diabetes.

Seeking input from patients regarding health engagement resources is crucial because HCPs may not have the necessary objectivity to identify the most useful engagement resources. People with diabetes of varying ages and life situations are sharing their experiences through health engagement resources. Relying on patients to help identify the most useful health

engagement resources ensures a synergy between patients' needs and the recommended resources. Remember that self-policing among individuals within online diabetes communities also helps to ensure that the most credible and useful resources gain validation and trust.

HCPs should ask their staff members and patients the reasons the resources they recommend are highly preferred and use that rationale to inform their own recommendations. Seeking input positions HCPs as curators and navigators on behalf of patients and decreases the appearance of bias or of "endorsement" by professionals.

2. Create a list of credible online resources to proactively share with patients during office visits.
Before sharing the list, HCPs should first access and review the recommended online resources to become familiar with what they offer patients. HCPs or health care organizations that have their own Web sites can also share resource links via their sites.

HCPs should use the opportunity to emphasize to patients that a diabetes care plan is based on individual needs. If patients want to make changes to their plan based on online information or conversations, they should first discuss the proposed changes with their HCP.

HCPs should emphasize characteristics that indicate that a resource may not be credible. These include sites that:
  Sell a specific product or service
- Display numerous advertisements, which may indicate potential for editorial bias
- Tout a quick fix or cure

- Use sensationalized stories and testimonials to persuade patients to take a specific action

Likewise, HCPs should teach patients how to recognize credible resources. These include sites that:
- Clearly identify the backgrounds and experience of the content author and the reason for sharing the information
- Offer a balanced perspective or information that is vetted and backed by a trusted organization such as the ADA
- Provide current and frequently updated content
- Seek input from credentialed medical advisors for any clinical content about diagnosis and treatment

3. Assess patients' use of online resources and level of health literacy.
Identify the health information and engagement resources patients are using, and gauge their level of understanding of such health information. Ask patients how the resources are helping them, and offer to address specific questions related to the information. Ask patients what tips and advice they would give other patients who want to reach out to online communities. Integrate this advice into ongoing discussions with other patients.

The number of patients who look online for diabetes-related information and resources is expanding. HCPs who proactively encourage patients to investigate reputable online health information and engagement resources may help improve their patients' problem-solving skills in managing diabetes day to day while also potentially strengthening the HCP-patient relationship.

REFERENCES

[1]Pew Internet & American Life Project: Profiles of health information seekers, 2011 [report online]. Available from http://www.pewinternet.org/Reports/2011/HealthTopics/Part-2.aspx?view=all. Accessed 26 November 2012

[2]Powers MA, March SB, Evert A: Use of Internet technology to support nutrition and diabetes self-management care. *Diabetes Spectrum* 21:91–99, 2008

[3]HealthEd Academy: Educational technology in the healthcare setting, 2012 [report online]. Available from http://www.healthedacademy.com/Home.aspx. Accessed 12 September 2012

[4]Wald HS, Dube CE, Anthony DC: Untangling the Web: the impact of Internet use on health care and the physician-patient relationship. *Patient Educ Couns* 63:218–224, 2007

[5]Ayers SL, Kronenfeld JJ: Chronic illness and health-seeking information on the Internet. *Health* 11:327–347, 2007

[6]University of California San Diego Health System: Social networking evaluated to improve diabetes self management [online press release]. Available from http://health.ucsd.edu/news/releases/Pages/2012-07-11-social-networking-and-diabetes.aspx. Accessed 24 January 2013

[7]DiaTribe: Proof is in the people [online blog post]. Available from http://diatribe.us/issues/50/sum-musings. Accessed 24 January 2013

[8]American Medical Association: AMA policy: Professionalism in the use of social media, 2012. Available from http://www.ama-assn.org/ama/pub/meeting/professionalism-social-media.shtml. Accessed 26 October 2012

[9]Diabetes Social Media Advocacy: #DSMA 20 June 2012 [Twitter chat]. Transcript available from http://bit.ly/RuNvdq. Accessed on 12 September 2012

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