

Back

[Home](#) [Departments](#) [Med Ed](#) [Search](#)

Search

In the News

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As Patients Turn to Web Communities, Physicians Must Take Notice



by Monica J. Smith

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Boston—Approximately 1.1 billion people have Facebook accounts, and the number of social media sites and users just keeps growing. Whether this trend forges relationships or increases isolation is an ongoing debate, but in the realm of medicine, social media that goes beyond the Yelp-like physician rating sites might enhance the patient experience and benefit physicians and their institutions as well, according to a group of experts who recently addressed the topic at a panel for gastroenterologists.

“As physicians, we can no longer ignore [social media]; we have to understand how patients are wanting to connect with us,” said M. Bridget Duffy, MD, chief medical officer at Vocera Communications, an information technology company that develops mobile communication devices and services for use in health care and other industries.

Dr. Duffy moderated a session on the emergence of social media in medicine at the 2014 [GI Roundtable](#), a conference dedicated to exploring challenges and their solutions for gastroenterology and the field’s future.

“Historically, we’ve focused on the intervention, but patients want us to connect with them before they arrive at the clinic or hospital. They want us to understand their preferences; they want a personalized plan and a path to their well-being; and they want a connectivity after they leave,” said Dr. Duffy, who has spent the past

20 years researching ways to improve the patient, staff and physician experience.

Dr. Duffy leads the Experience Innovation Network, a group of health care organizations committed to accelerating innovation on patient and staff experience. In addition, Vocera partners with Rock Health, a start-up incubator in San Francisco that mentors and supports medical tech companies dedicated to that goal. Dr. Duffy and her team participate in this mentoring and support, and help connect the companies to providers to test and adopt their novel products and services.

“We need to find technologies and process improvements that create consistent, seamless experiences of care, and that empower and engage patients to be partners in their care,” she added.

### **Cancer Connect—A Platform for Patients**

Social media, by definition, refers to the virtual communities and networks in which people generate, distribute and discuss information. Charles Weaver, MD, an oncologist and founder of Cancer Connect—a popular cancer information website—predicts this is how patients will interact with each other from now on. “The question for all of us is how do we become a part of it? How do we participate, and how do we use it to everyone’s best advantage?”

A pioneer of Internet-based patient education, Dr. Weaver got the idea to add a social media component to Cancer Connect after his elder son developed a rare sarcoma. Treatment required a long commute from their remote home in Sun Valley, Idaho, to the University of Utah Hospital. “I got to experience the fear, anxiety, confusion and isolation that any parent or patient experiences when they’re diagnosed with a significant illness,” Dr. Weaver said.

Fast forward several years, and Dr. Weaver found his sons engaged on Facebook one afternoon when they should have been doing homework. He was on the verge of scolding them when the younger one said, “Think if there was a Facebook just for cancer patients. Wouldn’t it be neat if they could connect with each other? They wouldn’t have to go through what [my brother] went through in a small town,” Dr. Weaver recalled.

His older son chimed in, “That would have been really helpful.” He had, in fact, already been using Facebook to locate and connect with other kids who had cancer.

The next day, Dr. Weaver called his programmers to discuss creating a Facebook-type of application just for cancer patients. Now, a little more than two years after Cancer Connect added its social media component, 52,000 people have registered to participate. Some 9,000 patients visit the physician-moderated virtual communities every month.

Users “are looking for validation of what their physician told them, for translations of what their physician said, and for support from others who have gone through their experience,” Dr. Weaver said. They “also told us that it was very important for them to give back. In fact, the patients we surveyed rated that as the most important aspect.”

### **Private-Label Communities**

Cancer Connect’s social media platform is free and open to any patient who wants to join, but it also is used by practices as a virtual home base for their patients. Dana-Farber Cancer Institute, Memorial Sloan-Kettering Cancer Center and Fred Hutchinson Cancer Research Center are just a few of the institutions that

use Cancer Connect to supplement supportive care of their patients and patients' families.

For such centers and practices, creating private-label communities has several advantages. On a practice's website, Cancer Connect is part of the patients' experience as it relates to that particular institution, an approach that may improve patient retention, increase patient referrals and enhance patient satisfaction, Dr. Weaver said.

The model works fairly simply. For example, from Dana-Farber's home page, a click on "My Dana-Farber" brings the visitor to an invitation to join their online cancer community. "It explains the rules of the community and how you participate in it. From that point on, the patient never leaves the experience of your brand and what you're providing," Dr. Weaver said.

Once a patient becomes part of Dana-Farber's online community, he or she can participate in both local and national conversations. They can choose to interact only with Dana-Farber patients, with patients from other centers using Cancer Connect, or both.

"The beauty of this is that for [cancers] that are common, you can build a community on your own website because you'll have enough patients to benefit from the experience," Dr. Weaver said. "With rare conditions, even a place like Dana-Farber won't have a critical mass of patients who can support each other, but by sharing the community with other large centers, you aggregate patients so they can get the support they need."

This need, of course, varies from one patient to another. Some visit Cancer Connect communities looking for an answer to a specific question or problem, whereas others desire a stronger connection.

"The ones who want a deeper relationship tend to find others who are also looking for a deeper level," Dr. Weaver said. "People initially join up because they want support and information. Those who stay want to share information and provide support, to give back," he noted.

### **GI Connection, a New Kid on the Block**

When Klaus Mergener, MD, PhD, MBA, of Digestive Health Specialists in Tacoma, Wash., learned about Cancer Connect and its offshoot, The [RA Connection](#), for people with rheumatoid arthritis, he quickly envisioned the utility of the concept for gastroenterology.

"We have a huge number of chronic diseases," Dr. Mergener said, from irritable bowel syndrome to cirrhosis. "If we can get a few hundred [GI] patients to start talking and connecting about their illnesses, I think that might be very useful."

He proposed the idea of a GI-specific platform to Dr. Weaver, and the two worked together to develop [GI Connection](#), which is scheduled to go live this summer. "GI and cancer have a couple of things in common," Dr. Weaver said. "The most important is that both specialties deal with chronic conditions, and people with chronic conditions want to stay connected."

"Also, they are both subspecialties that get their patients from someplace else—you're typically not diagnosed with cancer by an oncologist," Dr. Weaver continued. "This gives the subspecialties an opportunity to create communities to aggregate around the experience at their center."

Aside from patients with chronic GI diseases, those worried about an upcoming procedure might take comfort

in the support of others, too. “Connecting with someone who has had a colonoscopy or multiple colonoscopies and can tell you that it’s OK is very powerful,” Dr. Weaver said. “Sorry to say, but patients put a lot more value on one-to-one interactions with other patients than with health care providers.”

Before the launch of GI Connection, Dr. Mergener began raising awareness among practices that he hopes will be early adopters, mentioning the site to patients and increasing visibility with business cards and scannable QR codes. “Charles [Weaver] tells me that once you get up to 100 or 200 patients, involvement snowballs by word of mouth,” he said.

## **Crohnology**

As Sean Ahrens took the podium at the GI Roundtable to discuss Crohnology, the platform that he developed to capture the experiences of patients with inflammatory bowel disease (IBD), he acknowledged that physicians are his toughest audience.

“Partly, I think that’s because there is a wave, a front, of patients connecting back toward each other; the case I want to make to you is toward [the acquisition of] medical knowledge,” Mr. Ahrens said. “We are moving from the era of traditional media, where people are receiving information, to one in which they are contributing to the knowledge source.”

Mr. Ahrens was 12 years old when he experienced the onset of Crohn’s disease. Now 28, he has gone through a host of different treatments, or as he thinks of them, experiments. “These include physicians prescribing different medications, and me doing things like changing my diet,” he said.

Mr. Ahrens began to develop Crohnology as a college student, but the concept for the site gelled a few years later during one of his more unusual self-experiments. Remicade (Janssen Biotech; infliximab) was no longer controlling his symptoms, but he feared making the leap to Humira (AbbVie; adalimumab). Under the supervision of a physician who thought the novel therapy probably wouldn’t hurt him, Mr. Ahrens started inoculating himself with a pig whipworm solution he’d ordered from a company in Germany.

“During this treatment, it occurred to me that the very least I could do, as a favor to humanity, was leave a paper trail so that others could learn from this experiment,” he said.

It became clear about two-thirds of the way through that the pig whipworm therapy wasn’t working, as Mr. Ahrens’ symptoms remained severe. For the sake of his health, he adopted a specific carbohydrate diet, although he knew that it would compromise the quality of the data. But the experience further supported his theory that patients are vast silos of information, and that there should be a system to capture those experiences and learn from them, instead of dismissing each patient’s experience as anecdotal.

In 2011, Rock Health selected Crohnology as part of its inaugural class of start-ups to nurture. The support solidified development of [Crohnology](#)’s website and mobile platform. To date, the network has about 5,500 patient contributors with irritable bowel disease, representing 70 different countries.

As for that physician audience? Reactions have been mixed. “On the whole, physicians like the concept of connecting patients and giving them emotional and social support,” Mr. Ahrens said. “But they’re also generally of the school of thought that medical knowledge needs to be very carefully collected and dispensed inside the physician system, through rigorous clinical trials.”

He views Crohnology as a model that can accrue useful knowledge without the staggering costs of clinical trials.

### **Catching Up to the Consumer**

Ironically, although the increasing presence of technology has been criticized for creating barriers between physicians and patients, in the right hands, social media technology may be a way to start tearing down those walls, Dr. Duffy said.

“I think there is a way that technologies can be humanizing if you pick the right ones,” she said. “That’s what patients are doing through sites like Cancer Connect and Crohnology, using technology to create human connections with others who have conditions like theirs.”

One of her concerns with these technological innovations, however, is that physicians, who historically have been a bit recalcitrant with social media in their profession, are falling behind what their patients want and need.

“Doctors on the delivery side have to figure out how to find those resources that help restore people to a full life versus just a great technical outcome,” Dr. Duffy said. “And we have to move faster to catch up with where consumers are going.”



^ back to top ^

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