Social Media Interlopers in the Patient Communication Process

It happens frequently. A patient receives a dismal diagnosis. Surgery and a prolonged recovery period loom ahead and the physician says there is “nothing” else that will achieve the desired clinical outcome.

In other instances, a patient is undergoing treatment for a chronic ailment. She has reached a low ebb emotionally and physically. She wants something different other than the relentless and sometimes painful treatment for her ailment.

Then there are the cancer patients whose expectations of a prolonged remission are unrealistic. They seek out anything that suggests they are right and their care providers are wrong about the prospect of a long period of being cancer free.

In each instance there is a common theme: unmet or unsatisfied expectations. They all have the same questions, too. “Isn’t there something out there that is different that will help me?”

Patients may be encouraged to look elsewhere for answers by well-intentioned family and friends. They discourage patients from accepting the diagnosis or care plan provided.

It is somewhat ironic that as healthcare reform continues to promote ideas such as “patient engagement” and “patient-centered care,” patient use of social media may thwart such efforts. In today’s social media rich world, the patient may use a search engine to find blogs that
speak to their condition or needs. They may be referred to information via Facebook or Twitter links. YouTube and Google Video may have “interesting information” suggesting that indeed there is something different out there that looks like it is for them.

Some patients may use Twitter or go to a Facebook page from a bonafide disease-related association in search of an answer. Many may link to reports of new studies or journal articles. To the patient, a link or story may indicate a certain treatment or test that should have been done or that there is a different treatment modality to consider.

What happens when social media resources cause disintermediation in the care provider-patient relationship? What can it do in terms of continuity of care and clinical outcomes? What, if anything, should healthcare providers do to address social media as a dysfunctional and menacing interloper in caring for a patient?

The Hypothetic Case of Thad Glover.

Thad Glover thought he was better than the rest of the guys with whom he played squash three days per week. A fierce competitor on the squash court, he was also a great friend and colleague. He rarely saw a physician.

Three months ago, Thad noticed a spot on his right calf. He thought that it might have been a mosquito bite, but it did not seem to go away. Instead, it seemed to get larger, crust over and bleed. He tried some over-the-counter antibiotic ointments, but it did not help.

After a squash session with Hal Reading, a general practitioner, he mentioned the spot on his leg. “Let me take a look at it,” said Dr. Reading. After hearing the history from Thad and looking at the area he said, “I think you need to see a dermatologist about it. You know Ralph Story from the squash group across town. He is a well-respected dermatologist. Tell you what. I will telephone him today and tell him to expect a call from you. Don’t let this go, Thad. It needs to be seen,” said Dr. Reading.

Later that morning Dr. Reading spoke with Dr. Story. He described to him what he had found and said, “I am not an expert in melanoma, but this spot on his leg just does not look right to me. He says he first noticed three months ago. He is one of those guys who thinks he could never get sick. So be prepared when you see him.”
Thad Glover took Dr. Reading’s advice and called Dr. Story’s office. “Oh yes. Dr. Story said that you might be calling, Mr. Glover,” said the receptionist. She continued, “I have an appointment for you on Tuesday at 8:20 AM. Now all I need is some preliminary information and we can set it up.”

Thad Glover arrived for his appointment on time. After exchanging pleasantries with Dr. Story and asking about his squash game, Dr. Story said, “I spoke with Hal Reading and he thought you might have a skin problem that I should examine for you. So tell me when did you first notice it?”

Thad Glover gave him a detailed explanation and also told Dr. Story how he had tried to treat the spot himself. Dr. Story then examined the area and said, “Thad, this does not appear to be a mosquito bite to me. It is some type of skin lesion. The area is not well-defined. Notice too that it has multiple colors and one part of the area looks a lot different than the other area. And also, you said it was the size of an ink drop when you first saw it. Now as I measure it, the area is larger than the diameter of a pencil. I think we ought to biopsy the area and make certain that it is not something serious.”

Thad Glover said, “What do you mean by serious?”

Dr. Story replied, “Thad, I do not wish to alarm you, but this could be a form of skin cancer. We will know as soon as the pathologist can examine the biopsy sample that I send to her.”

Thad Glover agreed to the biopsy. Dr. Story gave him written instructions for taking care of the area. He thanked Dr. Story and left the office feeling concerned.

Three days later, Thad received a voice mail message on his cell phone from Dr. Story. “I think it would be a good idea if you and I met later today. I have the results of the skin biopsy and we need to talk about a care plan for you. I asked the receptionist to give you a noontime appointment. If this time is not convenient, call the office and give the receptionist another time today,” said Dr. Story.

Thad took the noon appointment. Dr. Story said, “Please have a seat. The biopsy results indicate that you have melanoma, a serious type of skin cancer. Based on the report, I think you need surgery to remove a large area around the spot to make certain that it has not spread. I will also order a series of blood tests. What we want to do is establish that we get clean margins around the area. By that I mean that there is no evidence of any melanoma cells spreading beyond the initial site. If there
is any question about the area, you can anticipate further diagnostic work, including a CT and a PET scan. First things first. Let us find out what we have in terms of the affected area. I can arrange for the surgery to be done within the next few days. I am sorry to give you such news, Thad, Do you have any questions?"

Thad Glover was overwhelmed, especially after he heard the word “cancer.” His grandfather and an uncle had also had melanoma and both had died from the disease. He told Dr. Story to go ahead and get the ball rolling for the surgery.

Thad took the rest of the day off. He went home and told his wife, Lynne, what had happened. “What?” she said. “You did not tell me that you had gone to a dermatologist. Cancer? Melanoma? That is very, very serious Thad. Are you sure this guy knows what he is doing? I think you need to get a second opinion.”

Mrs. Glover spoke with her sister, her brother, and two college classmates who had become well-respected internists. They gave her references to share with Thad that could be found on the Internet. On her own, Mrs. Glover checked out blogs, YouTube, and other sources.

She was not certain that he husband had gotten sufficient information. “I think you need to speak with Larry Matterson, my college classmate. He is a great internist. And also, I found all these resources online for you. Come on, Thad. It is your health. Take control,” she said.

Thad did as his wife suggested. He spoke with Dr. Matterson. He also reviewed blogs, corporate, non-profit and personal websites, a melanoma patient listserv as well as some video material on YouTube. He decided to call Dr. Story.

“Thad, what can I do for you?” said Dr. Story. He continued, “I thought everything was all set for Friday. Have you changed your mind? My assistant said that you had some concerns about the surgery.”

Thad told him about his discussion with Dr. Matterson and the review he had completed of the information that his wife had found online. “I just think I do not have a complete picture. I have never been a patient before and I want to make certain I am doing the right thing,” said Thad Glover.

Dr. Story replied, “I have a suggestion. Come on in later today and with your permission, ask your wife to come with you. Bring with you the references you found online. Let us go through this together so that you
are clear about what is involved with the diagnosis, the surgery, and the follow-up. I’ll see you later today.”

The Glovers met with Dr. Story after his last appointment for the day. “I just feel overwhelmed. My grandfather and uncle died of melanoma. I never even thought anything like melanoma could happen to me.”

“Oh? You never mentioned having a family history of melanoma, Thad,” said Dr. Story.

“Yeah. I do not remember you asking me about it, either. My brother and sister get checked out every year and I thought they were crazy. I am not certain what to do, especially after talking with Dr. Matterson and seeing all the stuff Lynne found for me online,” said Thad Glover.

Dr. Glover replied, “Okay. Let us start from the top. Let us talk about what the pathologist found, what is recommended in terms of surgery and what you have found from speaking with friends and family members and also what you found online.”

After a 30-minute session, Dr. Glover said, “Do you have any questions about what we discussed? Lynne, what is your understanding about the plan?” And then “Thad, I want you to tell us both what you understand and importantly, what you want to do.”

Thad and Lynne Glover gave very accurate explanations of the proposed care plan. They agreed that the surgery was the right approach. Thad signed a consent document for the procedure and after the Glovers left, Dr. Story dictated a detailed note in the office record about the discussion with the couple.

The surgery was uneventful. The pathologist reported that Dr. Story had been able to obtain clean margins. Mr. Glover was put on a follow-up protocol that included regular head-to-toe examinations for other lesions.

Observations on the Glover Case.

The Glover case is a good illustration of what can happen as a result of social media disintermediation of the care provider-patient relationship. Add to it that family also weighed in with their advice and one can see how easy it is for patients to become overwhelmed with competing sources of information.
By his own admission, Mr. Glover had not been a patient. He admitted to Dr. Story that he felt overwhelmed. Understandably, knowing that his grandfather and that his uncle had died from melanoma worried Thad Glover.

What could have been done differently to avoid such a situation? First, Dr. Story did not seem to know that Mr. Glover had a family history of melanoma. Thus history-taking could be improved.

Second, in today’s world, care providers should anticipate that patients and their loves ones will use the Internet, and especially social media resources to “fact check” the care provider. Many people may be more inclined to believe blogs and online videos from non-experts, people “just like them” over “biased” or “mainstream” sources. This may be especially true with those who are dubious or are confronted with a menacing diagnostic or treatment journey.

Third, in a patient-centered model, care providers might encourage the patient to ask if he or she would like a spouse, sibling, another relative or a trusted friend to take part in a discussion of diagnostic or treatment options. Patient permission documented in writing is prudent for this purpose. Having another “set of eyes and ears” can help in terms of the two-way discussion about the diagnostic and treatment alternatives. Not only might such a person serve as a source of emotional support; in some instances the third party might encourage the patient to share additional information or prompt the individual to ask pertinent questions.

Finally, the Glover case demonstrates why it is important to equip patients with trusted online resources for further information about the diagnostic or treatment options at their disposal. In doing so, care providers should counsel patients to refrain from relying on unreliable resources.

Dr. Story acted reasonably once it became clear that the patient and his wife had doubts, based on an array of sources presenting conflicting information. Yes, it did involve an additional period of time to weed through the information. However, what Dr. Story did was to restore confidence and galvanize the care provider-patient relationship. That he documented this extra step was important, particularly if there were an untoward outcome following the surgical intervention. The additional conversation reflected a sincere effort on his part to achieve patient-centered communication and to set a reasonable expectation about the patient’s condition and treatment.
Practical Strategies for Handling Social Media Resources in the Patient Communication Process.

There are a number of practical measures to consider in managing patient use of and reliance on social media resources, including the following:

1. **Establish Expectations on Social Media in Office Practice Signage and Patient Documentation.**
   Take advantage of in-office televised programming and patient information signage to dispel misunderstandings about disreputable social media resources and unsubstantiated or dated claims or reports. Point out the dangers of relying on unfounded assertions found in some social media resources and other websites. Encourage patients to discuss with his or her care provider use of reputable social media information, such as YouTube channels from certain professional associations, or provider- or expert-moderated forums. *[See Sample Tool]*

2. **Provide Patients with Trusted Social Media Resources.**
   Develop a consistent approach of offering patients well-established and reputable social media resources to examine – do not assume that patients or families will easily distinguish between those YouTube channels belonging to a legitimate professional organization and those posted by an anti-pharmaceutical, anti-medical or conspiracy-promoting group or individual. Be certain to check regularly that recommended resources are current, and that the information provided is accurate. Beware that otherwise legitimate sites may link – automatically – to sites that are not. Maintain a schedule and log for checking social media resources offered to patients. Document in the medical record the list of social media resources and disclaimers provided to the patient.

3. **Use a Teach-Back Process Following Patient Exploration of Social Media Resources.**
   Utilize a teach-back style communication with patients to determine which social media resources on the suggested list were examined. Go further, asking about additional social media information found by the patient. Ask if the patient has any questions about either recommended or self-identified social media resource information. Ask a series of open-ended questions to confirm patient understanding of agreed-upon diagnostic tests or treatment. Instead of asking, “Do you feel like you have a good understanding of the test?” ask the patient, “Tell me, now that you have reviewed the suggested sites and social media resources, what is your
understanding of the operation that you have agreed that I should do next week?” Document the patient’s responses in the medical record.

4. **Clarify Any Concerns with the Patient Regarding Information Found in Social Media Resources.**
Be poised to engage the patient in additional discussion, particularly if the teach-back process reveals misunderstanding or concerns stemming from social media resources. Complete the clarification process with a series of open-ended style questions to confirm patient understanding of agreed upon tests or treatment. Document in the medical record the clarification and repeat teach-back process.

5. **Reinforce with Office Personnel the Importance of Channeling Social Media Questions to the Care Provider.**
Emphasize with clinical and administrative personnel in the office to refer to the care provider questions raised by patients about information gleaned from social media resources. Instead of staff saying, “Oh, well you can always find information like that on YouTube,” encourage them to respond to the patient by saying, “You have posed a question that I think the doctor would appreciate discussing with you directly. Let me get her for you.”

**Conclusion.**

Social media is all about users themselves creating content easily – videos, blogs, and websites online. It can provide a rich array of useful information to help patients understand recommended diagnostic tests and therapeutic treatment. The experiences and links provided can offer patients data about options as well as the potential drawbacks of pursuing such alternatives.

Some patients may trust information on a blog of online video over the “mainstream” media, or in preference to official websites or channels of a medical association, company or government agency. Many patients may believe that the content is “unbiased” because it did not come from an organization they distrust or that they believe may financially benefit from their condition. Other patients may feel that the views or experiences of a “fellow patient” are more relevant – or more “real.”

Content found online amongst social media sites can confuse, overwhelm, or scare a patient. The result may be a disruption in the care provider-patient relationship.
Rather than experience social media disintermediation of the care provider-patient relationship, effective steps can be followed to harness the power of reputable websites, vetted blogs, expert-moderated forums, and vetted YouTube channels into effective ancillary tools or decisional aids to facilitate patient decision-making. Taking such steps can help set and maintain reasonable patient expectations and patient satisfaction.
The following language could be incorporated into a practice brochure or on the website of a medical practice. It is intended to put in context the use of social media resources as a tool to facilitate communication between care providers and patients.

**What to Look for in Reputable Healthcare Social Media Resources**

There is a lot of information on diseases and treatments in social media, from websites, YouTube, Google+, My Space, Facebook, and Blogs. Some of the information may be dated and no longer relevant. Sometimes the information is misleading or flat out wrong. Relying on such resources can raise false hopes about treatment. It can also take away hope or trigger needless fear about medical tests or treatment.

In our practice we provide our patients with trusted social media resources. We regularly review material made available from well-respected medical specialty groups, physician and expert-moderated patient resource groups, and others to develop a list of social media information that is timely, accurate, understandable and most of all, reputable.

Beyond giving our patients trusted social media resources, we go one step further. We encourage our patients to review the information and then to discuss this information with their care provider.

Our practice views our patients as partners in the delivery of good medical care. This means that care providers and patients alike both need information that is consistent that they can discuss with one another.

We ask our patients to tell us if they find other useful resources in their use of social media resources. We want to discuss this additional information with them as well.

If at anytime there is a question or concern about something found in a social media resource, please discuss it with your care provider. The same applies to information and advice offered by family and friends. As a partner in your healthcare experience, please be certain to discuss this information with your care provider.