Com municating about chronic illness on social media sites can be beneficial, but can it also be harmful?

IN 2014, PEW Research Center reported that 74 percent of adults interact socially on the Internet. Whether it’s Twitter, Facebook, Reddit or Tumblr, social media platforms have one thing in common: self-disclosure. They are sites where people often reveal personal information about themselves to friends, acquaintances and, sometimes, strangers.

Hundreds of types of messages for as many different reasons are posted on social media sites. The quick, harmless posts range from “Lasagna for dinner tonight!” to vacation highlights, complete with “Wish you were here” tags and pictures. But, there are also the potentially harmful personal posts about feelings and well-being. Due to the very nature of the Internet, which promotes scanning over careful reading — not to mention that text is devoid of tone — it becomes difficult to determine when these types of posts are appropriate or not.

For chronically ill people and their friends and family, social media sites can become the canvas upon which their emotional and physical health is publicly displayed. Most of us have seen examples of this. For instance, someone wants their online friends to know they’re feeling particularly ill, so they “overshare” about their diagnosis, posting gritty details in hopes they offer catharsis, understanding or both. Upon reading these posts, some might feel sympathy and reach out, whereas others might feel uncomfortable and pull away. And when this type of information is repeatedly shared, some might begin to view the poster of these messages in a different, sometimes undesirable and awkward light. Whether such a response is fair is beside the point, but knowing that negative perception is a possibility is helpful when using social media.
Benefits of Social Media

Like all forms of technology, social media is neutral: It can be used for healthy and unhealthy purposes. The good news is that social media has proved helpful to many chronically ill patients.

Health forums such as Inspire and PatientsLikeMe can be especially helpful because they allow patients and healthcare providers to share important information such as news relating to clinical research and drugs. They can also help patients form caring friendships with those who understand a particular condition, often providing encouragement, personal accountability regarding treatment, treatment tips and inspiration. According to one Inspire user, “The health community I’m part of helps because I am understood — the struggles, the pains, the mysteries, the hard road to getting appropriate medical care and treatment, the disappointments and despair, and the quirky triumphs. I love sharing the triumphs, some of which would be meaningless to others. I also feel useful when I can support and offer assistance in any way to my fellows, and that is very important to my self-esteem.”

Social media can even help patients find the best doctors and promote advocacy among those with chronic illness. People understand the importance of social media communities. A 2014 survey of PatientsLikeMe users revealed a majority of members were willing to share their health information if it helps others patients or even advances treatment and helps doctors to know more about an illness.³

Pitfalls to Navigate as a Patient

But there are risks and challenges with social media usage for patients.

In forums, for example, it can be difficult to find accurate information. Unless there is an active moderator who checks facts, what is shared is often “folk wisdom.” “The Internet is full of anecdotal data, not systematic information,” explains Portland, Ore., psychologist Joseph Rhinewine, PhD. “When you go into a forum or other online group and ask, ‘What medication should I use to treat my fibromyalgia?’ you’re going to get people’s opinions. That means nothing for you. A study of one is scientifically untenable.”

There’s also the risk of “oversharing” about life or a condition. Craving attention and seeking affirmation from outside sources is common; patients want to let others know they’re struggling in hopes of finding help and relief. Emotional relief is often found in forums and online support groups that connect people with the same disease. But, on sites where others may not understand about a particular sickness, excessive sharing can be awkwardly perceived.

Patients must determine their own motivations for posting about their condition. That might seem subjective, but there are questions they should ask themselves before publishing their thoughts for the world. First, are they using social media too frequently? “If you believe you’re using it in excess, then you probably are,” says Dr. Rhinewine. It’s important to understand, he adds, that excessive social media usage can cause depression rather than provide comfort.⁴

To determine whether social media usage is excessive or detrimental in other ways, Dr. Rhinewine says the next thing to look at are values: “What do you want your life to have been about after the 100 years are over? Check whether or not your behavior is lined up for that. If it isn’t, look at where it’s really incongruous and see if it would be worth realigning [with your goals and hopes] even if that’s very uncomfortable for you.”

For chronically ill people and their friends and family, social media sites can become the canvas upon which their emotional and physical health is publicly displayed.

“With chronic illness, one of the things that are corrosive about social media is the fact we often begin to identify with our disorder,” explains Dr. Rhinewine. “And that can become a central aspect of people starting to squeeze out what is terrifically meaningful in their lives as it becomes less and less central in their self-definition.” Online forums, he says, are helpful in many ways, but they can also strengthen the tendency to over-identify with an illness. Therapists can help patients to transform that energy into something more meaningful and positive such as a hobby, friendships or even education.

Tips for Caregivers and Friends

What healthy social media usage looks like is highly subjective, and what patients deem is healthy may look unhealthy to others. While only patients can fully understand their motivations, their
The freedom of more personal time with HYQVIA, the only once-a-month subQ Ig*

For adults with primary immunodeficiency (PI)

Schedule an appointment with your physician to see if HYQVIA is right for you.

* subQ Ig, also known as subcutaneous immune globulin.

Please see the Indication and Important Risk Information on the adjacent pages and the Brief Summary of HYQVIA Prescribing Information on the reverse side.

To learn more about HYQVIA, visit www.HYQVIA.com
HYQVIA [Immune Globulin Infusion 10% (Human) with Recombinant Human Hyaluronidase] is the only once-a-month subQ Ig with recombinant human hyaluronidase (hy•a•lo•ni•dase) and Ig. The hyaluronidase temporarily opens the subQ space, allowing a larger amount of Ig to reach the subQ tissue and be absorbed into the bloodstream to help fight infection. It’s the reason you can infuse your monthly dose of HYQVIA using 1 needle, 1 infusion site, 1 time a month.

INDICATION AND USAGE
HYQVIA [Immune Globulin Infusion 10% (Human) with Recombinant Human Hyaluronidase] is an immune globulin with a recombinant human hyaluronidase indicated for the treatment of Primary immunodeficiency (PI) in adults. This includes, but is not limited to, common variable immunodeficiency (CVID), X-linked agammaglobulinemia, congenital agammaglobulinemia, Wiskott-Aldrich syndrome, and severe combined immunodeficiencies.

Limitation of Use: Safety and efficacy of chronic use of recombinant human hyaluronidase in HYQVIA have not been established in conditions other than PI.

Detailed Important Risk Information
HYQVIA can cause serious side effects. Call your healthcare professional or go to your emergency department right away if you get:

- Hives, swelling in the mouth or throat, itching, trouble breathing, wheezing, fainting or dizziness. These could be signs of a serious allergic reaction.
- Bad headache with nausea, vomiting, stiff neck, fever, and sensitivity to light. These could be signs of swelling in your brain.
- Reduced urination, sudden weight gain, or swelling in your legs. These could be signs of a kidney problem.
- Pain, swelling, warmth, redness, or a lump in your legs or arms, other than at the infusion site(s). These could be signs of a blood clot.
- Brown or red urine, fast heart rate, yellow skin or eyes. These could be signs of a liver or blood problem.
- Chest pain or trouble breathing, blue lips or extremities. These could be signs of a lung problem.

These are not all the possible side effects with HYQVIA. Talk to your healthcare professional about any side effects that bother you or that don’t go away.

What is the most important information that I should know about HYQVIA?

- HYQVIA can cause blood clots.
- Call your healthcare professional if you have pain, swelling, warmth, redness, or a lump in your legs or arms, other than at the infusion site(s), unexplained shortness of breath, chest pain or discomfort that worsens on deep breathing, unexplained rapid pulse, numbness or weakness on one side of the body.
- Your healthcare professional may perform blood tests regularly to check your IgG level.
- With your consent, your healthcare professional may provide blood samples to Baxter Healthcare Corporation to test for antibodies that may form against the hyaluronidase part of HYQVIA.
- Do not infuse HYQVIA into or around an infected or red swollen area because it can cause infection to spread.
- Talk to your healthcare professional if you become pregnant. Women who become pregnant during HYQVIA treatment are encouraged to enroll in the HYQVIA Pregnancy Registry by calling Medical Information at 1-866-424-6724.

What are the possible or reasonably likely side effects of HYQVIA?
After HYQVIA infusion a temporary, soft swelling may occur around the infusion site, which may last 1 to 3 days, due to the volume of fluid infused. Mild or moderate pain, redness, swelling, or itching may occur at the site of infusion and generally go away in a few hours.
Eligible patients on a prescribed Shire Ig product with commercial insurance can save up to a total of $5,000 within a 12-month period on their deductible, co-payment, or co-insurance for medication costs with MyIgCoPayCard. This program provides financial support for all Shire Ig products regardless of household income. Patients are eligible for a maximum benefit of $5,000 in total Shire support within a 12-month period to:

- Help ensure that patients with PI have access to Shire Ig treatment
- Lessen the burden of out-of-pocket expenses for Shire Ig treatment

*Not valid for prescriptions reimbursed, in whole or in part, by Medicaid, Medicare, Medigap, VA, DoD, TRICARE or any other federal or state healthcare programs, including state pharmaceutical assistance programs, and where prohibited by the health insurance provider or by law. Commercial insurance must cover medication costs for prescribed Shire Immune Globulin (Ig) treatment for primary immunodeficiency (PI) and allow for copay or co-insurance assistance. Shire reserves the right to change or discontinue this program at any time without notice. Please see full treatment-specific Terms and Conditions on product web sites for additional program restrictions and eligibility requirements or call MyIgSource for more information (855-250-5111).
Once a month or more frequently, if needed.†

INDICATION AND USAGE
HYQVIA is an immune globulin with a recombinant human hyaluronidase indicated for the treatment of Primary Immunodeficiency (PI) in adults. This includes, but is not limited to, common variable immunodeficiency (CVID), X-linked agammaglobulinemia, congenital agammaglobulinemia, Wiskott-Aldrich syndrome, and severe combined immunodeficiencies.

Limitation of Use:
Safety and efficacy of chronic use of recombinant human hyaluronidase in HYQVIA have not been established in conditions other than PI.

Important Risk Information about HYQVIA

HYQVIA can cause blood clots. Call your healthcare professional or go to your emergency department right away if you have pain, swelling, warmth, redness, or a lump in your legs or arms, other than at the infusion site(s), unexplained shortness of breath, chest pain or discomfort that worsens on deep breathing, unexplained rapid pulse, numbness or weakness on one side of the body. These could be signs of a blood clot.

Do not use HYQVIA if you are allergic to immune globulin (IgG), hyaluronidase, or other blood products, or have IgA deficiency.

These are not all the possible side effects with HYQVIA. Talk to your healthcare professional about any side effects that bother you or that don’t go away.
The following summarizes important information about HYQVIA (pronounced Hi-Q-via). Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare professional.

**What is HYQVIA?**

- HYQVIA is a liquid medicine containing immune globulin and Recombinant Human Hyaluronidase. HYQVIA contains IgG antibodies, collected from human plasma donated by healthy people. The antibodies help your body to fight off bacterial and viral infections. The hyaluronidase part of HYQVIA helps more of the immune globulin get absorbed into the body to fight infection.
- HYQVIA is indicated for the treatment of Primary Immunodeficiency (PI) involving the humoral immune system in adults.
- Safety and efficacy of chronic use of recombinant human hyaluronidase in HYQVIA have not been established in conditions other than PI.
- **HYQVIA is for subcutaneous use only.**

**What is the most important information that I should know about HYQVIA?**

- **HYQVIA can cause blood clots.**
- **Call your healthcare professional if you have pain, swelling, warmth, redness, or a lump in your legs or arms, other than at the infusion site(s), unexplained shortness of breath, chest pain or discomfort that worsens on deep breathing, unexplained rapid pulse, numbness or weakness on one side of the body.**
- Your healthcare professional may perform blood tests regularly to check your IgG level.
- With your consent, your healthcare professional may provide blood samples to Shire to test for antibodies that may form against the hyaluronidase part of HYQVIA.
- Do not infuse HYQVIA into or around an infected or red swollen area because it can cause infection to spread.
- Talk to your healthcare professional if you become pregnant. Women who become pregnant during HYQVIA treatment are encouraged to enroll in the HYQVIA Pregnancy Registry by calling Medical Information at 1-866-424-6724.

**Who should not take HYQVIA?**

Do not take HYQVIA if you:

- Are allergic to IgG, hyaluronidase, other blood products, or any ingredient in HYQVIA.
- Have IgA deficiency with antibodies to IgA.

**What are the possible or reasonably likely side effects of HYQVIA?**

- Antibodies to the hyaluronidase component of HYQVIA were formed in some patients taking HYQVIA. It is not known if there is any long term effect. In theory, these antibodies could react with your body's own PH20. PH20 is present in the male reproductive tract. So far, these antibodies have not been associated with increased or new side-effects.
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- Brown or red urine, fast heart rate, yellow skin or eyes. These could be signs of a liver or blood problem.
- Chest pain or trouble breathing, blue lips or extremities. These could be signs of a lung problem.

These are not all of the possible side effects for HYQVIA. You can ask your healthcare professional for information that is provided to healthcare professionals. Talk to your healthcare professional about any side effects that bother you or that don’t go away.

**What should I tell my healthcare professional before I start using HYQVIA?**

Before starting HYQVIA, tell your healthcare professional if you:

- Have or had any kidney, liver, or heart problems or history of blood clots because HYQVIA can make these problems worse.
- Have IgA deficiency or a history of severe allergic reactions to IgG or other blood products.
- Are pregnant, trying to become pregnant or are breast feeding.

**How should I take HYQVIA?**

- HYQVIA is infused under the skin (subcutaneously) up to once every 4 weeks.
- You can get HYQVIA at your healthcare professional's office, clinic, or hospital.
- You can use HYQVIA at home. You and your healthcare professional will decide if home self-infusion is right for you.

You are encouraged to report suspected side effects by contacting FDA at 1-800-FDA-1088 or www.fda.gov/medwatch or Shire at 1-800-999-1785.

The information provided here is not comprehensive. To learn more, talk about HYQVIA with your healthcare provider or pharmacist. The FDA-approved product labeling can be found at www.HYQVIA.com or by calling 1-800-423-2090.
perspectives can become skewed. Even so, caregivers and friends need to be careful about giving advice. “Many believe that when you don’t know [what else to say], just give your opinion,” says Dr. Rhinewine. “That’s what many psychologists are doing across my field, and I think it’s really harming the public. I don’t want to contribute to the ‘this is what you should do’ mentality. People’s thoughts don’t work the way you think they will, and they often don’t respond to what common sense would seem to dictate.”

To illustrate, Dr. Rhinewine says, “If a caregiver or friend were to see that a patient seems to be identifying excessively with their illness through social media, the worst instinct a caregiver or friend could have would be to say something like, ‘Hey, maybe you shouldn’t talk about it so much.’ That could be profoundly invalidating for a patient. The caregiver and friend don’t know what function [social media] is serving for the chronically ill person. That could be the very best thing for them right now and exactly what they should be doing.” In situations in which a caregiver or friend knows the patient really well, he says it’s possible to diplomatically say, “Hey, I think you might want to back off of this.” But, in most instances, “offering concrete advice is almost invariably perilous.”

Acting as a sounding board, rather than a black-and-white advice-giver, can be much more beneficial. “It may be that if you know the patient well, you could gently encourage them to see a qualified therapist,” Dr. Rhinewine says. “Sometimes that kind of advice or gentle nudging is welcome. Even if it’s unwelcome, the person might reluctantly go with it and still benefit.”

Kathleen Franco, MD, a psychiatrist at the Cleveland Clinic, shares many of Dr. Rhinewine’s thoughts, but her instruction for friends, family and caregivers is perhaps a bit more prescriptive for helping a chronically ill person to stop oversharing on social media: “If you believe that someone is seeing primarily the illness in themselves, and not their other good qualities, then help them to see themselves outside of that light.” There are many ways to do this, Dr. Franco explains, one of which is to ask: “Would they go out to do something with you?” This could be taking a walk together, volunteering at a charity, working with animals, taking a class — anything that could help the person stretch their perspective on themselves and their situation.

Dr. Franco also stresses to friends and caregivers that a patient who seems to misuse social media is often driving people away unintentionally, without understanding what’s happening. “The patient becomes a martyr, and they intensify their efforts to inappropriately reach out because it’s all they’ve known,” she explains. “At some point, reaching out in that manner has brought them closer to people, but they must learn to develop another focus and plan for relationships. They have only a plan A, so to speak, and they need to learn things about themselves that they and others will appreciate.”

A Patient Who Seems to Misuse Social Media is Often Driving People Away Unintentionally, Without Understanding What’s Happening.

Weighing the Benefits vs. the Pitfalls

Social media sites can offer many benefits for patients, including a place to connect with others with the same disease, as well as to share information about lifestyle and treatments.

But, patients must also be cautious about what they post and how their postings affect them and others. Before posting anything on social media, patients should ask themselves a few questions. Is what they are saying kind, true and valuable to others? Would they say it face to face? Could what they are expressing be selfish in some way? Is social media actually increasing their frustration by enabling or encouraging them to vent? What is posted online stays online in some form for years. Are they posting things they won’t be embarrassed about next summer — or two decades from now? Will they regret saying it?

No one can provide patients and caregivers absolute answers about appropriate use of social media. But, with careful thought and gentle guidance, it’s possible to reap more benefit than harm.

MEREDITH WHITMORE is an English professor and freelance journalist in the Northwest.

References