How I Nearly Outed Someone's Hepatitis C Status: A Cautionary Tale

October 24, 2016 By Lucinda K. Porter RN

Recently I posted a message of praise about an article discussing someone's story of living with hepatitis C. I posted it to their Facebook page. Although they are now cured, it never occurred to me that this person might not want the entire Facebook community to know that they had hep C.

I've been an advocate in the hep C community for nearly 20 years, and I am shocked by my insensitivity. Fortunately, this person had set their Facebook privacy settings to require approval for all external postings. In short, although I acted thoughtlessly, no harm was done. But, the foul was committed, and my penance is to devote this month's Healthwise to a discussion on privacy.

Why is there a need for privacy about hepatitis C? Because of stigma. Hep C is stigmatized for a variety of reasons:

- Hep C is potentially infectious. Although it isn't transmitted as easily as some think, humans can be quite fearful about infectious diseases. People may react strongly out of their fear of "getting" hep C; so much so, that they may act irrationally. Fear and ignorance have cost patients their jobs, friendships and relationships. Some people with hep C have been shunned by their communities.
- Another aspect of the stigma relates to hep C's association with injection drug use. People and societies often lack compassion and understanding about injection drug use. Former injection drug users may feel haunted by their past and want to avoid this label. Active injection drug users who can't avoid the label, carry the burden of having two stigmatized diseases, addiction and hepatitis C.
- Stigma may also affect those who have never used injection drugs. Misinformed people sometimes assume that all people with hep C have used injection drugs despite the many ways hepatitis C may be acquired. Those without a history of drug use do not want to be labeled as

injection drug users. Despite the fact that we need to stop marginalizing drug users, it is understandable when a non-drug user might not want this extra layer of stigma.

Stigma may cause us to look for others like ourselves. The impersonal nature of the internet can feel like a safe place to find others with hep C, a place to exchange information about how to live with this disease. However, the internet is not a private place. In fact, it is the ultimate public place. Not only do we have to worry about the inadvertent postings by careless people like me, now we have to worry about WikiLeaks.

In August, WikiLeaks published medical information belonging to private citizens, including peoples' hepatitis C status. Wiki revealed information about HIV, sexually-transmitted diseases, mental health, victims of rape, and much more. Private identity information, such as addresses was included in these leaks.

Not only is nothing private on the internet, it is forever. Information cannot be erased from the web. So, if you don't want people to know about your having hepatitis C, don't tell anyone. However, if WikiLeaks can hack into your medical record, then there isn't much you can do to protect yourself.

The only way through this that I can see, is that we need to combat stigma. I am not sure how to do this, but I think it starts with unity. Collectively, we must stand together. We can hold each other up, and defend each other as we confront ignorance.

As for my nearly outing someone, I hope I learned my lesson. The decision to go public is a personal one. Although I have never regretted living publicly with hepatitis C, it was not without consequences. Fortunately, I was not alone, and when I felt the sting of stigma, you were quick to help me mend.

In botany, the word stigma refers to the part of a plant where bees deposit pollen. The stigma bears the fragrant sweet solution that attracts bees. It is a place of fertilization. For those with hepatitis C, it may be the place where shame blossoms into hope. It is time to bring hepatitis C out of the closet and into the sunshine. But only if you are ready. The decision is entirely yours. And if you step into the public arena, I stand ready to walk with you.

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