
Social Media in Healthcare: The Patient's Perspective

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By Clarissa Schilstra

The diagnosis of such a serious illness, whether it is acute like cancer or chronic like Type 1 diabetes, can leave a person feeling isolated and lost. You wonder why it has happened to you, and you may feel isolated or lost. Fortunately, through a variety of social media and online resources, I found a way to cope with those challenges after I was given a life-threatening diagnosis.

Just before I turned 13, I was diagnosed with a relapse of the same leukemia I had at age 3. After my diagnosis, a social worker came to speak with my family and informed us about a website called CarePages. Through CarePages, my family created a blog and posted updates on all that I was going through throughout my 2-1/2 years of treatment. In this way, we were able to keep our family and friends all around the world regularly informed without worrying about phone calls or e-mail.

I also received an enormous amount of support through the family and friends who visited my page and posted many caring and hopeful comments. Their support helped me to stay positive throughout my treatment.

Because of CarePages, I found two other teenage girls who also had gone through treatment for a late relapse of leukemia. We became friends, and they provided me with a great deal of advice.

More importantly, they let me know that I was not alone, that my "rare" relapse did not mean my life was over.

Aside from CarePages, there were not many resources available for teens with cancer. Therefore, I decided to create one.

I originally wanted to develop a small book, filled with advice on how to get through the various stages of diagnosis, treatment and survivorship. With help from various people, including my parents and a doctor we had met through family friends, I began my journey to develop a book by creating a blog.

I published www.teen-cancer.com in 2011, and continue to post on it today. While I set out to simply make it a resource for other young people going through cancer treatment, it has actually become very therapeutic for me as well. Writing blog posts has been a very positive experience because it has enabled me to process my journey through cancer treatment and life as a two-time cancer survivor.

I think that making social media tools more accessible to patients, directly after a significant diagnosis, should be a priority for healthcare providers. In addition, I firmly believe that there should be a greater focus on providing age-specific resources to patients.

As a teenager, I found myself being treated around very young children, but dealing with a very different set of social and emotional challenges than them. I can only imagine that the same situation occurs in other settings, whether it be a 23-year-old going through health challenges along middle-aged adults with established families and professional lives, or a 40-year-old mother going through cancer treatment alongside retired, elderly people.

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Therefore, it is crucial that resources be explored as a viable means to help patients with their age-specific challenges.

Social media resources can offer very effective tools for this. I found Facebook and Twitter useful; you can easily use them to search for organizations and groups. Through Facebook, I came across three different teen cancer support organizations and was able to get to their websites filled with many helpful resources.



Furthermore, social media outlets enable patients to reach out to people going through similar healthcare experiences at similar stages in life. Additionally, such sites are much more flexible than structured support services, like support groups. Through these virtual methods, patients can connect with others who can understand what they are going through, even while being confined to a hospital bed or sofa at home. Patients can, however, choose to form supportive groups from those connections if they would like.

During my treatment, I rarely felt well enough to meet new people. I preferred communicating virtually with other teen cancer patients and survivors during my treatment. Once I finished my treatment, and felt well again, I worked together with friends I had made in the hospital to co-found a support group for teens with cancer.

This transition from virtual to personal support paired perfectly with my transition from patient to survivor, and was all possible because of social media and the online resources I found through it.

I would like to hear from other patients who have had similar experiences in finding a support group through social media. Please share your thoughts here on the HIMSS Blog.

Clarissa Schilstra is a student at Duke University and a two-time survivor of leukemia. Since entering remission in 2009, Clarissa has worked to channel her experiences as a patient to help other young cancer patients. She has served as a Johns Hopkins Pediatric Oncology Patient Ambassador, co-founded a support group for teenage cancer patients, and started a [blog](#). Clarissa is the Vice-President of Blue Devils vs. Cancer, a student organization dedicated to raising funds and awareness for cancer research and cancer patients. She is a psychology major and hopes to attend medical school.

She is the author of a chapter in *Applying Social Media Technologies in Healthcare Environments* (HIMSS Books, 2014), which is available in [print](#) and [eBook](#) editions.



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