

Facebook status: Sick—how people use the internet to cope with illness

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Credit: Petr Kratochvil/public domain

When a person is diagnosed with a serious illness, he or she may seek support from a variety of sources: friends, family, support groups,



medical and mental health professionals. Today's toolkit for coping with disease also includes something it didn't in the past: digital resources.

In his new book, <u>mitpress.mit.edu/books/coping-illness-digitally</u>>*Coping with Illness Digitally*, University of Arizona communication professor Stephen Rains explores how people use <u>digital tools</u> like social media, online <u>health</u> forums, medical information websites and even email correspondence with physicians to cope with <u>illness</u>.

As these tools have become more widely available, they have changed the ways in which patients understand and come to terms with disease diagnoses, and even how friends and family members grieve when a loved one dies, says Rains.

"Because technology has become so central to our lives, it makes sense that it would also be used as a coping resource," said Rains, who studies technology and health. "I saw this book as an opportunity to do two things: One, to better understand the world in which we live, in which we're inundated with these technologies that play such a central role in our everyday lives. And two, to learn about how people cope and how resourceful people are in making sense of and dealing with illness."

Rains' book pulls together research from a variety of fields, including communications, medicine, public health, psychology and sociology. In it, he proposes a model for understanding how and why patients engage in digital coping activities, based on seven benefits afforded by technology: anonymity, availability, control, diversity, documentation, reach and visibility.

For example, after a patient is diagnosed with a serious or lifethreatening illness, one of the first things he or she might do is seek more information about the condition online, where massive amounts of diverse material are available at one's fingertips and the user has control



over the extent of the search.

Patients might also post on their <u>social media</u> accounts or blogs as a way to share their disease journey, giving them visibility, reach and a way to document their experiences, for themselves or loved ones. In addition, they might visit or post comments in online health forums for others with similar diagnoses—something they can do publicly or anonymously.

"Online communities have been around since the '80s and '90s in different forms, but now they're a lot more prominent, and 1 in 5 people has gone online at some point in their life for peer support," Rains said. "The reason people go online is because the experience of illness, in many ways, sets them apart and makes them different from their family and friends, who want to help but don't know exactly what that person's going through. Sometimes, going online and talking with others who are experiencing similar things allows people to realize they're part of a broader community who's all in this together, and just knowing there are others online feeling the same way is very comforting."

Rains' book also includes a chapter on end of life and bereavement, which explores how friends and <u>family members</u> use digital tools in grieving.

"One finding in a couple studies that really struck me was evidence that people use Facebook pages to talk with the bereaved," he said. "They use these technologies to maintain a relationship with someone who passed away."

While it's easy to focus on the potential social pitfalls of life online, the research in Rains' book suggests the digital space is largely beneficial for those diagnosed with serious illness.

"When we talk about online, we often talk about it in negative



terms—cyberbullying, negativity online—but in the context of health, I see almost the polar opposite," Rains said. "If you go into these online support communities, by and large they tend to be very warm, inviting, positive and supportive places."

Provided by University of Arizona

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