

# Seeking Social Solace



How Patients Use Social Media to  
Disclose Medical Diagnoses Online

PREPARED BY



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## How Patients Use Social Media to Disclose Medical Diagnoses Online

Few events are as life-changing and overwhelming as the moment someone learns he or she has been diagnosed with a serious illness. Not only can such news be personally devastating, one of the greatest struggles can be sharing the news with family and friends. As Lynne Eldridge, MD, observes in "The Turmoil of Telling Your Loved Ones You Have Cancer," research suggests that talking with family is the most difficult task.<sup>1</sup>

As recently as a decade ago, individuals primarily shared news of a serious medical diagnosis through traditional means – face-to-face conversations, telephone calls and handwritten letters. But as social media has fundamentally transformed how consumers communicate, has the way we converse about illness changed in step? The answer to this question has implications for healthcare professionals, behaviorists, nonprofit organizations and those they serve.

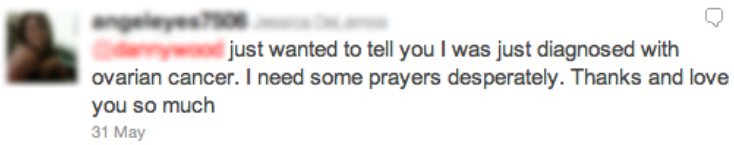
To learn more, social media analysts at Russell Herder, a strategic marketing firm headquartered in Minneapolis, employed sophisticated online monitoring technology to survey the prevalence – and content – of post-diagnosis conversation. The results were profound.

### The Tech-Savvy Patient

Without a doubt, the web has created a wealth of opportunity for healthcare consumers. According to a recent report from the Pew Internet Project and California HealthCare Foundation, 80 percent of U.S. Internet consumers seek health information online, making it the third most popular activity behind email and the use of search engines.<sup>2</sup> Those who go online to find health information are usually facing either their own or a family member's serious medical crisis, the study observed.<sup>3</sup>

While many Americans turn to friends and family for support and advice when they have a health problem, they also use the Internet to expand their support networks to include online peers, particularly in the instance of rare disease. Nearly one in five (18 percent) U.S. Internet users has gone online to find others who have experienced similar health issues, according to the Pew study.<sup>3</sup>

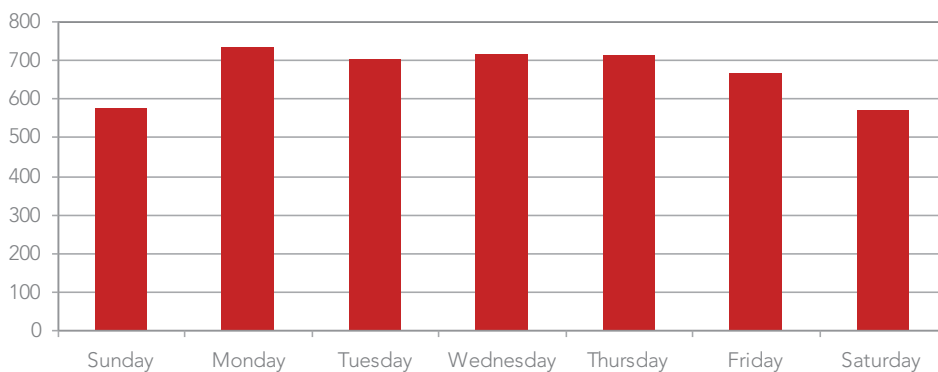
Health-specific networking websites such as PatientsLikeMe.com and DailyStrength.org serve as a central location for online education and support for any number of acute and chronic conditions. The highly popular service, CaringBridge.org, allows patients and families to share their medical journey through easy-to-build webpages. Disease-specific sites like GroupLoop.org, which serves as a resource for teens with cancer and their families, offer patients a highly personalized online experience. Indeed, the “traditional” web has emerged as a tremendous resource for healthcare consumers. It therefore comes as no surprise that social media platforms like Facebook, Twitter and blogs have also increasingly become routine settings for discussions regarding the most personal of concerns.



## Taking It Online

But when do people share news of a devastating illness? And which platforms do they choose to use? To find answers to these questions, Russell Herder researchers explored phrases such as “I tested positive for,” “I’ve been diagnosed with,” “Doctor said I’ve got” and many more. Over a 90-day period, 62,893 online self-disclosures of an illness were tracked.

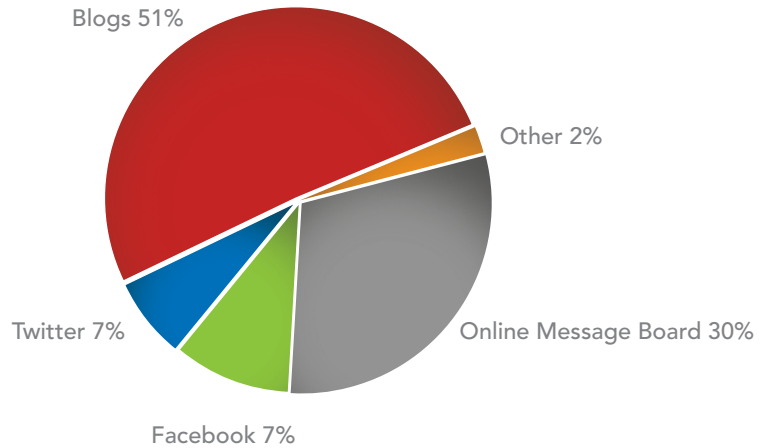
Diagnosis Self-Disclosures by Day of the Week



While such conversations were relatively steady, a distinct pattern emerged regarding self-disclosure by day of the week. Online, people disclosed their illnesses on weekdays (average of 706 occurrences

per day) 23 percent more frequently than they did on weekends (average of 575 occurrences per day). As diagnoses may often occur at outpatient clinics during normal business hours, could this distribution suggest that patients are more likely to share related news online immediately or shortly after learning of their condition rather than waiting for days before doing so?

## Diagnosis Self-Disclosure by Social Media Platform



Social monitoring was also able to reveal which online channels were used most frequently for self-disclosure. Fifty-one percent of such comments occurred in blogs, 10 percent on Facebook and 7 percent on Twitter. It is important to note that postings on Facebook were likely understated due to the fact that pages with stronger privacy settings cannot be accessed.



Carol Cheek

April 11, I was diagnosed with "Invasive Ductal Carcinoma" (breast cancer). Had lumpectomy April 21. So far negative in traveling any further, was very small mass, too deep and too small to be felt.

The choice of communication channel may reflect different motivations for self-disclosure of a serious illness. For instance, comments on blogs, Facebook and micro media such as Twitter may be the most direct indicator of the digital age's impact on communication preferences with family and friends. In contrast, patients disclosing through online message boards may be offering support of others experiencing similar situations. Such virtual comments may also be a reflection of a need for support not being met by providers, family and friends.

## I AM SO VERY SCARED.

I could not sleep last night thinking about what might happen on Tuesday. I am having an ultrasound scan and think I may have a biopsy so I am really worried and frightened, I don't want to find my cancer has returned.

## What Are They Saying?

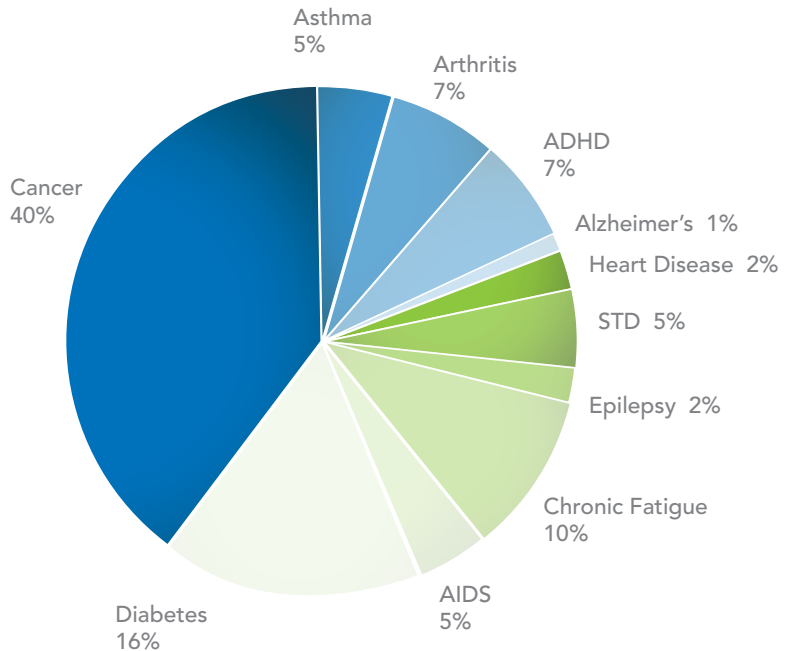
What does someone say when they talk about his or her illness online? Comments are as individual as the writer, but a look at the conversation cloud generated during the research indicates a high concentration of introspective words including “think,” “time,” “love,” “feeling,” “little,” “things” and “question.” There is clearly a more expressive purpose to such conversations versus communicating technical details.

Conversation Cloud



Interestingly, the type of disease appears to influence someone’s motivation to announce and discuss it online. Cancer is disclosed more frequently online than other major illnesses. A deeper look reveals interesting trends. In 2010, there were 27 times more cancer diagnoses (1,529,560<sup>4</sup>) than there were HIV/AIDS diagnoses (56,300<sup>5</sup>). Cancer was only disclosed nine times more frequently, however, which suggests people are more likely to disclose a diagnosis of HIV/AIDS online than cancer.

Self-Disclosure Diagnosis by Condition



Furthermore, there were more new diagnoses of diabetes in 2010 (1.9 million<sup>6</sup>) than cancer in 2010. Yet, compared to diabetes, cancer was disclosed more than twice as frequently. As diabetes may be considered more manageable and less life threatening than cancer or HIV/AIDS, perhaps there is a correlation between the lethality of a disease and the likelihood that one will disclose his or her diagnosis publicly in an online environment.

With cancer being the most disclosed disease, social media analysts at Russell Herder drilled deeper to see if any specific types were revealed more often than others.

Breast cancer received nearly the same number of online self-disclosures as prostate cancer, colon cancer, leukemia, bone cancer, non-Hodgkin lymphoma, lung cancer, skin cancer, pancreatic cancer, testicular cancer and brain cancer combined. Yet, according to the American Cancer Society, there were 831,530 new cases of the type of cancers mentioned above, compared to 209,060 new cases of breast cancer – a nearly fourfold difference.<sup>4</sup> New cases of prostate cancer (217,730) and lung cancer (222,520) actually exceeded new cases of breast cancer.<sup>4</sup>

Why do breast cancer patients gravitate to making announcements in social media more often than others? The answer may lie in demographics. According to one recent study, women – the gender predominantly affected by breast cancer – are heavier users of social media.<sup>7</sup> Also, there are more online resources and destinations for those interested in breast cancer. A Google search for breast cancer returned 97.1 million results compared to only 25.9 million for lung cancer and 28.9 million for prostate cancer.

## What Healthcare Professionals Can Do

What does this information mean for healthcare organizations and providers? The following are a few observations made by Russell Herder social researchers:

### Go where they are.

Given the growing demand for online access to health-related information and support, hospitals, clinics and organizations should ensure they are providing the social media and website resources their patients and prospects are seeking.

### Care for the mind as well as the body.

Consumers' apparent proclivity to disclose their condition relatively soon after diagnosis may underscore the need for emotional support after they receive the news. Providers and organizations that support them should make sure that they are providing appropriate resources for their patients on all levels.



Russell Herder is a marketing and research firm located in Minnesota. For more than 28 years, the firm has provided integrated strategic solutions for leading healthcare organizations across the U.S. For more information, visit [russellherder.com](http://russellherder.com) or call 612.455.2360.

## Empower your support network.

The willingness of those diagnosed with serious illness to lend support to others is profound – and clearly reflected within the volume of blogs and commentary. Providers should find ways to further harness this network of mentors to assist in the healing process.

## It's what you say – and how you say it.

The language recently diagnosed patients use when discussing their illnesses online suggests the need for provider communication that is understanding and compassionate. Though consumers generally rely on health professionals for technical advice about their diagnoses and treatments, they more often call upon friends, family and fellow patients for emotional support. While that may be appropriate, providers can potentially increase their level of patient care by using tonality reflective of true patient-centered care.

## Reach out.

There may be an opportunity to support communities currently underserved in the digital realm – such as prostate or lung cancer patients. With fewer online destinations available for these diseases – and incidence rates significant – additional online means of sharing information may be useful.

## Understand the boundaries.

It is not unusual for those with chronic health issues and long-term medical problems to build close relationships with care providers. Should a nurse, for instance, accept a Facebook “friend” request from a grateful cancer patient? The legal, ethical and practical issues that emerge can be difficult. There has been much conversation on how providers can establish appropriate boundaries, yet help meet patient needs for health education and support. One solution comes from Dr. Keely Kolmes, a San Francisco psychologist, who publishes a social media policy to help keep appropriate boundaries in place.<sup>8</sup> The issue is not one quickly resolved for providers or consumers, but both sides need to consider what makes sense.

### Footnotes

- 1) Eldridge, Lynne, MD, “The Turmoil of Telling Your Loved Ones You Have Cancer,” About.com, August 2008.
- 2) Fox, Susannah, “The Social Life of Health Information,” Pew Internet, February 2011.
- 3) Fox, Susannah, “Peer-to-peer Healthcare,” Pew Internet, May 2011.
- 4) American Cancer Society, [www.cancer.org/acs/groups/content/@epidemiologysurveillance/documents/document/acspc-026210.pdf](http://www.cancer.org/acs/groups/content/@epidemiologysurveillance/documents/document/acspc-026210.pdf).
- 5) Centers for Disease Control, <http://aids.gov/hiv-aids-basics/hiv-aids-101/overview/statistics>.
- 6) “National Diabetes Fact Sheet 2011,” Centers for Disease Control, [www.cdc.gov/diabetes/pubs/pdf/ndfs\\_2011.pdf](http://www.cdc.gov/diabetes/pubs/pdf/ndfs_2011.pdf).
- 7) Work, Sean, “Who Likes What: Social Media By Demographic,” <http://blog.kissmetrics.com/social-media-by-demographic>, February 2011.
- 8) [www.drkkolmes.com/docs/socmed.pdf](http://www.drkkolmes.com/docs/socmed.pdf), April 2010.