

Cancer Patient Blogs: How Patients, Clinicians, and Researchers Learn from Rich Narratives of Illness

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Abstract. *Blogs written by cancer patients can offer deep insights to other patients about what to expect in the course of illness and treatment, can provide information to oncologists and other clinicians about patient experiences outside of appointments, and can increase researcher awareness of treatment effects and alternatives. While many forms of social media and online communities are used by patients, blogs are unique in that they provide a narrative of many aspects of disease and treatment, offering a comprehensive view of the disease experience delivered in installments, often from diagnosis through life as a survivor. However, the impact of patient blogs has been modest thus far because patient blogs are spread across the internet and, with no central repository of patient blogs, opportunities for analysis are limited. Given the life-altering and potentially devastating impact of cancer on people's lives, we seek to develop a tool that will analyze tens of thousands of patient-authored blogs to improve cancer patient care.*

Keywords. Blogs, narratives, social media, patients, clinicians, reserachers.

1. Introduction

Given the potentially devastating and life altering impact of cancer on people's lives, we seek to use available internet content, namely patient blogs, and existing tools for mining and analysis to improve cancer patient care. Patient blogs are something people write or read on their own that has not been well researched or integrated into the patient-doctor relationship. Clinicians do not, as a rule, recommend writing or reading blogs to patients, nor are they likely to read or even know about their patients' blogs.

Researchers rarely turn to blogs as a source of qualitative data about patients' experience of illness. Blogs written by cancer patients and survivors, through their rich narrative about their diagnosis, treatment, or life after cancer, can offer insights to other cancer patients about what to expect in the course of illness and treatment, can provide information not otherwise available to oncologists and other clinicians about patient experiences outside of appointments, and can offer researchers a trove of qualitative data about treatment effects and alternatives to guide their investigations into new treatments.

Creating a repository of blogs written by cancer patients and analyzing them will serve three audiences, namely:

1. Cancer patients, who will more easily find blogs that match their needs based on the relevance of the content of the blog or characteristics of the author of the blog;
2. Oncologists, nurses, and other people treating patients ("clinicians"), who will be able to learn about specific aspects of the experiences of patients with a diagnosis or treatment in order to more effectively treat their own patients;
3. Researchers, who can investigate how cancer patients react to diagnoses, develop coping strategies, and experience and mitigate side effects of treatments..

2. Blogs as an emerging source of qualitative data

Blogs are in essence online diaries that allow individuals to share narrative stories with text, pictures, and video clips, part of the latest generation of Web 2.0 technologies (Boulos, Maramba, & Wheeler, 2006). Blog posts are dated and each can be commented on and tagged with keywords that describe its content (Keim-

Malpass, Baernholdt, Erickson, Ropka, Schroen, & Steeves, 2013). Although other forms of social media garner much of the focus for online communication, consumer interest in blogs continues to grow. It is estimated that 19 million people blog today (Nielsen, 2012). The increasing use of blogs has been reported in several studies (Kim & Chung, Characteristics of cancer blog users, 2007). Amongst online collaboration technologies, social networking sites (14.8%) and blogs/micro-blogs (14.1%) are the most commonly used tools (Hamm et al, 2013). Blogging has grown significantly in recent years; an estimated 181 million blogs existed globally by the end of 2011, compared with 36 million only five years earlier (Nielsen, 2012).

While patient blog topics can be on a range of health issues, from weight loss and fitness to all types of chronic disease, cancer patients may be among those most in need of vehicles for support. Patient blogs range from ones with hundreds of thousands of readers, such as Dana Jennings' prostate cancer blog or Suleika Jaouad's young adult cancer blog, each in the New York Times, to ones with a small number of readers on WordPress, Blogger, and other websites.

In them, cancer patients write about their thoughts and insights throughout the course of their treatment and survivorship, such as in the following excerpts from Dana Jennings' post (<http://well.blogs.nytimes.com/2010/02/15/after-surviving-cancer-a-focus-on-true-manhood/>):

After a radical open prostatectomy, radiation and hormone therapy, it's still difficult to get the old engine of desire to turn over. And now that I'm dosing my post-treatment depression with Zoloft — which also disrupts sexual function — sometimes I can't even find the key.

and an excerpt from a post by a breast cancer patient

(<http://www.butdoctorihatepink.com/2013/05/stereotactic-radiation-decisions.html>):

Let's keep up hope though, and say it is successful and does kill the tumor. I could likely be off chemo for a while, which would be amazing. Maybe I could even have a period of normal living again. Maybe I could travel, visit friends and family and knock some things off my to-list. Maybe I could just do normal things like cook and eat. That would be incredible.

Patient blogs are a valuable source of information and support (Kim, Content analysis of cancer blog posts, 2009) yet all but the most prominent are difficult for other patients to locate. Further, while their qualitative data could offer clinicians and researchers a rare insight into the experience of cancer from a patient perspective, patient blogs are largely unused for this because, with no central repository of patient blogs, opportunities for analysis are limited. Other sectors, such as retail, have successfully used blogs as a means of learning from the "voice of the customer," but much less has been done in healthcare in general and cancer in particular.

Social media and user-generated data are increasingly studied as a rich source for analysis. Google Flu Trends, for example, which estimates flu activity based on aggregated search queries, can detect regional outbreaks of influenza seven to ten days before conventional Centers for Disease Control and Prevention surveillance systems can (Carneiro & Mylonakis, 2009). Health apps and online communities including PatientsLikeMe.com provide tracking tools for patients with cancer and other diseases, (Frost & Massagli, 2008) but the tracking information is rarely enhanced with the qualitative information that helps in understanding the complex experience of illness. While patient blogs are not a form of social media commonly analyzed, Twitter and Facebook are and we can utilize research strategies from the techniques used in other research. Public health departments analyze social media sites such as Twitter to assess constituents' communication about chronic disease (Harris, Mueller, & Haire-Joshu, 2013), and clinicians recognize the importance of utilizing social media to disseminate health information (Vance, Howe, & Dellavalle, 2009).

There are seven themes of online health resources: finding information; feeling supported; maintaining relationships with others; affecting behavior; experiencing health services; learning to tell the story; and visualizing disease (Ziebland & Wyke, 2012). Patient blogs differ from other online health resources and social media because each centers on the experiences of one person, with no specific format constraining or guiding their communication. Through readers and comments, a micro-community is formed around that person and his or her illness. Patient blogs are included in patient sites including CarePages and CaringBridge, (Anderson, 2011) but, since these are generally password-

protected, they are not included here as a form of patient blog. There are a few group blogs as well, such as Mayo Clinic's "Sharing Mayo Clinic" and MD Anderson Cancer Center Cancerwise, but because many patients are interspersed in both, they do not provide the continuous unfolding narrative of an individual patient.

3. Use of blogs by patients to write about the experience of illness

Understanding the psychosocial and emotional consequences of chronic disease is an important aspect of many healthcare disciplines, including medicine, nursing, psychology, social work, and sociology (Carr, Loeser, & Morris, 2005). Because they provide a way for both patients and family members to reflect, connect, and find meaning, illness narratives are often recommended (Pennebaker, 2000). Extensive medical and social science research has examined the use of patient narratives as methods of telling the story of illness and health and demonstrated the psychological and physical benefits associated with patient illness narratives (Ressler, Bradshaw, Gualtieri, & Chui, 2012). While expressive writing in medicine is not a new phenomenon, online communication technologies allow patients to express their experiences of illness to a larger, real-time audience and facilitate sharing and comments (Ressler, Bradshaw, Gualtieri, & Chui, 2012).

Of US internet users, 26% say they read or watched someone else's experience about health issues and 16% say they went online to find others who share the same health concerns (Fox & Duggan, 2013). While many forms of social media and online communities are used by patients, blogs are unique in that they provide a narrative of many different aspects of disease and treatment, offering a comprehensive view of the disease experience delivered in installments, often from diagnosis through life as a survivor. It is estimated that 19 million people blog today, a number that has grown significantly in the last five years (Nielsen, 2012). The number of patient blogs is not known, however there are more than 24,000 health or health-related blogs currently indexed (Technorati, 2013). The largest number of these is about cancer, and women with or survivors of breast cancer are particularly active on the internet (Quinn, et al., 2013).

4. The potential impact of patient blogs on cancer patients, clinicians, and researchers

More than 15 million Americans are living with or have survived cancer (United States Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute, 2013). The American Cancer Society estimates that almost 1.7 million new cancer cases will be diagnosed in 2013 in the United States alone (American Cancer Society, 2013). Prostate, breast, and lung cancer have the highest incidence rates (National Cancer Institute, 2013). Cancer – the diagnosis, its treatment, and the near and long term effects – often have devastating impacts on patients' lives (Schover, 1991) (Karp, Chiarodo, Brawley, & Kelloff, 1996).

Blogs represent a new form of communication, one that shifts the control of information to those who read and write them (Kim & Chung, Characteristics of cancer blog users, 2007). Blogs present an opportunity for cancer patients, practicing oncologists, and clinical researchers to discuss findings and suggestions and to share emotional support in all aspects of cancer-related treatment (Oransky, 2005). At a time when patients may feel they have lost control of many aspects of their lives, this can be a particularly important and advantageous aspect of blogging (Kim & Chung, Characteristics of cancer blog users, 2007).

Blogs written by cancer patients have the potential to offer several benefits throughout the health continuum of care. Online data through patient blogs represent a new and innovative way of capturing the naturalistic experience of the cancer journey (Keim-Malpass, Baernholdt, Erickson, Ropka, Schroen, & Steeves, 2013). Furthermore, they offer a way to combine diary-like patient entries with the internet's ability to create and facilitate online social networks (Keim-Malpass, Baernholdt, Erickson, Ropka, Schroen, & Steeves, 2013), thus expanding their potential usefulness for cancer patients.

A study about the motivation for patient blogging revealed the primary themes of 1) helping others, 2) decreasing sense of isolation, 3) sharing of experiences, and 4) finding a sense of community and authentic voice within an individual's co-existence with a chronic illness (Ressler, Bradshaw, Gualtieri, & Chui, 2012). The 230 patient blogger respondents who completed a survey about the psychosocial and health benefits of blogging were predominantly

female (81.8%) and highly educated (97.2% > high school education and 39.6% with graduate school or professional degrees) (Ressler, Bradshaw, Gualtieri, & Chui, 2012). This blogging study used a “snowball” convenience sample so may not proportionally represent the demographics of patient bloggers but a fuller picture is not available. While patient bloggers are a self-selected group, that in no way limits the value of what they write but means that there are many experiences of illness that are never documented in this format. When other demographic factors are held constant, having a chronic disease significantly increases an internet user’s likelihood to say they work on a blog or contribute to an online discussion, a listserv, or other online group forum that helps people with personal issues or health problems (Fox & Duggan, 2013). Certainly the internet, particularly social media, enables people to engage with each other and with health care in ways that were almost unimaginable a decade ago (Fox, 2011).

While patient blogs are available on the internet and are therefore, in theory, possible to locate, they are hard to find and there is no established mechanism to make it easier to find patient blogs in general or blogs on specific topics in particular. Blogger-defined subject tags and software-generated subject tags are often overly broad or overly narrow in focus, producing less than effective search results for those seeking to extract information from cancer blogs (Kim, Content analysis of cancer blog posts, 2009). The patients who write blogs are unlikely to invest effort in creating and using more than a rudimentary set of tags that are unlikely to aid, say, a researcher concerned about issues of adherence to specific treatments or a newly diagnosed patient seeking blogs written by patients with specific demographics or diagnoses. Additional exploration into methods for systematically organizing cancer blog postings is necessary if blogs are to become stable and efficacious information resources for cancer patients, friends, families, or providers (Kim, Content analysis of cancer blog posts, 2009). Yet this may require more effort or time than most patients want to commit, and pose an arduous task for clinicians or researchers to accomplish manually.

If cancer patients seek to learn from the experiences of others, the first difficulty they face is to locate blogs matching their needs, interests, and perspectives. To search the internet

effectively in general, and specifically in support of patient relevant information, is difficult (The Daily SEO Blog, 2010). Sophisticated search algorithms exist in many consumer-focused domains, allowing someone to search in a dating site for someone matching very narrow criteria or to locate a movie through a recommender engine based on past likes and dislikes.

The most likely ways to find patient blogs are through the few sites that include them, such as the aforementioned cancer blogs in the New York Times; through the few directories of cancer blogs, such as Navigating Cancer & Blood Disorders, that list blogs by cancer type alone, with a limited number of cancer types and a limited number of blogs within each category; through other forms of social media, such as following a cancer patient on Twitter who promotes his or her blog in the Twitter profile, or through a generic search engine. In the latter case, where 80% of patients’ health searches begin (Fox & Duggan, 2013), “cancer blog” returns over a half million results and the specialized blog search Google provides returns almost 100,000 results. While many results are patient blogs, the results are sorted based on ranking metrics which are defined by search engine companies for profit motives and have given rise to multitude of search engine optimization companies that specialize in working with commercial sites to achieve higher search rankings (Brin & Page, 1998). In addition to patient blogs, search results include many other types of health and news sites. Thus finding a patient blog that meets a patient’s specific needs requires laboriously sifting through many results.

5. Creation of a patient blog repository

Our first innovation is therefore to create a repository of patient blogs in which a patient can search for a blog based on type or specific criteria. To accomplish this we must (1) define what makes good matches based on patient needs and measures of quality (filtering out blogs promoting products or erroneous information, for example); (2) set up a mechanism to search for blogs on the internet on an ongoing basis (since the content is not static); (3) set up a process for people to submit blogs to the repository; (4) set up a mechanism to tag blogs based on their content; and (5) develop and test a specialized search engine for cancer patients that returns and ranks result in a visually effective display.

Our second innovation, once the repository of patient blogs has been created, is to extract knowledge from them for multiple perspectives, including: (1) providing textual summaries of individual blogs to patients or clinicians; (2) creating timelines of the course of a patient's disease and treatment based on dated entries and content analysis, thus enabling a visual summary; and (3) creating a mechanism for answering questions about cancer patients' reaction to diagnoses, development of coping strategies, adherence to treatment, experience and attempts to mitigate side effects of treatments, use of CAM, and other aspects of life as a cancer patient.

6. Future Directions

The proposed work has the potential to create a better experience of treatment once a patient has been diagnosed with cancer. Given that cancer patients write blogs and that many suffer during treatment, we propose to use these existing patient blogs to improve care by making it easier for other patients read helpful blogs, providing more information to oncologists and other clinicians about what cancer patients experience, and facilitating researchers' ability to ask questions about specific aspects of treatment. This can alter not only how a patient deals with treatment adherence and side effects, but also how clinicians and researchers understand and design treatment protocols. This can result in improvements in quality of care and changes in health policy, potentially leading to better health outcomes.

7. Acknowledgements

Our gratitude to the many people who contributed to this research, most especially Susan Parsons, MD, MRP, Pam Ressler, MS, RN, HN-BC, Libby Bradshaw, DO, MS, and Ken Chui, PhD, MPH, MS and to the cancer patients who inspired us, in particular, the cancer blogger who inspired us, Gary Klatsky, PhD.

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