PatientsLikeMe: Empowerment and Representation in a Patient-Centered Social Network

Jed R. Brubaker

Department of Informatics
Donald Bren School of
Information and Computer
Sciences
University of California, Irvine
{ jed.brubaker }at uci.edu

Caitlin Lustig

Department of Computer Science
Donald Bren School of
Information and Computer
Sciences
University of California, Irvine
{ clustig } at uci.edu

Gillian R. Hayes

Department of Informatics
Donald Bren School of
Information and Computer
Sciences
University of California, Irvine
{ gillianrh } at ics.uci.edu

ABSTRACT

We examine the patient networking site PatientsLikeMe relative to current trends in medicine toward patient-centered care and empowerment. We focus on both patient and institutional demands for personal medical data. Given PatientsLikeMe's mixture of social networking and health management tools, we consider the role of online health communities in the changing patient/provider relationship, and the use of patient-provided medical data.

Author Keywords

Online health communities, social networking, personal health information.

INTRODUCTION

A recent email newsletter from the heath-focused social networking site PatientsLikeMe invites users to "Join the Conversation." Founded in 2004, PatientsLikeMe (PLM) currently provides fourteen different "disease communities" in which approximately 47,000 patients interact using social networking tools akin to those seen on Facebook and health management tools similar to those found in personal health record systems (PHR). This particular newsletter was targeted at a group of users with mood conditions including depression, anxiety, and post-traumatic stress disorder. It highlighted several "hot topics" in the forum including threads such as "understanding your triggers," "name ten things you like about yourself," and "I'm worthy." These conversations are well aligned with PLM's espoused belief "in getting to know the person, not just the 'patient.'"

The site's overall objectives, however, are not completely clear given a goal of providing anonymized user data to pharmaceutical companies and the medical industry. This relationship between patient communities and the desire (at least in part) to profit from their participation calls into question motivations behind the design of sites like PLM, as well as community newsletters that encourage users to "help other patients by updating your profile today."

In this paper we consider PLM relative to two important topics in the medical informatics and CSCW communities:

patient-centered care, in which patients and clinicians are a collaborative team, and the various demands for medical data from both patients and institutional interests. Combining features from both PHR and social network sites (SNS), PLM attempts to address demands for patient-centeredness and involvement through empowering patients in the treatment of their diseases. Interactions are predominantly inter-patient and do not include medical professionals, raising questions about the potential of favoring peer advice over prescribed treatment plans. Additionally, the collection and sale of user data prompts questions related to data ownership, use, and validity. Ultimately, adoption of PLM points to the importance of online spaces in which patients can share experiences and receive peer-support consistent with their treatment plans. Investigating the ways in which PLM captures, stores, and presents health information inside of a social network context provides important implications for the design of collaborative patient systems such as PHRs and other online health communities.

BACKGROUND

PLM was developed to facilitate information sharing between patients within disease-specific communities. In addition to general SNS tools such as user profiles, comments, and private messages, each community provides disease specific tools that allow patients to track and share relevant information such as symptoms, treatments, and medical data. These features allow users to compare their experiences to other patients and can empower them to take a more active role in determining treatment options with their care providers. Users can choose from a number of privacy options, but PLM places a decided emphasis on their "Openness Philosophy," a statement that advocates a democratization of patient data via the Internet in order to "accelerate research like never before."

PLM's hybrid blend of SNS, PHR, and research data warehouse places it at the intersection of debates over technological advances and patient empowerment. The literature on telemedicine and e-health enumerates a

mixture of outcomes resulting from patients' online behavior [7,11]. Research shows participation in online patient communities can provide important social and emotional benefits [9], particularly when offline options are unavailable [17]. Moreover, patients derive the greatest benefit when interacting with others who share their medical conditions [12], notable given PLM's segmentation of users into disease communities.

Providers, meanwhile, have concerns over shared medical data and the potential for a patient's non-adherence with a doctor prescribed treatment plan [1,13]. Clinicians often question the accuracy of information on the Internet [2], and evidence suggests that patients in online communities have limited understanding of necessary medical terminology [15]. As such, patients may be under-equipped to evaluate medical information without the assistance of a medical professional, leading to additional concerns associated with self-diagnosis and cyberchondria [18].

Despite the concerns of medical professionals, the growth of PLM confirms a growing trend of users looking beyond the traditional boundaries of the patient-provider relationship for information and support [4]. As such, PLM presents a novel space in which to consider patient-centered care and patient generation and use of medical data. These themes are currently being considered in other academic, industry, and policy work in medicine – notably around Electronic Medical Records (EMR) and PHRs.

PATIENT INVOLVEMENT & PATIENT-CENTERED CARE

The Institute of Medicine listed patient-centered care as one of six objectives for a 21st century health system [8]. Providing care that is "respectful of and responsible to individual patient preferences, needs, and values" includes the "empowerment of patients and their families in effective management of health care decisions" [16]. "Health 2.0," in particular, refers to a number of new technologies aimed at empowering patients. Examples include patient websites

(*e.g.,* WebMD) and social networking sites such as PLM, as well as patient portals and PHRs.

Although PLM has received a largely positive response from public news media (*e.g.,* its inclusion in CNN's "15 companies that will change the world"), the site presents both the patient's disease and the medical industry as barriers to be navigated. Some Health 2.0 technologies attempt to improve cooperative patient-provider relationships through, for example, integrating PHRs with provider health records. PLM, however, aims to empower patients in leveraging the knowledge and experience of peers, stating, "YOU can take control of your disease." Profile charts "let you see how your treatments affect your health over time," while users are encouraged to share information and experiences with other "patients like you."

The role of care providers in online patient communities such as PLM, as well and the ways in which to best align the patient-provider relationship and patient support, remains unclear. PLM users actively engage in social interactions, solicit advice, and foster relationships [5]. However, because PLM is an independent site, doctors may view patient participation as a risk to the patient-provider relationship. Although doctors and medical providers are allowed on PLM, their role is largely limited to observations and social interaction with which to better understand patients in a given disease community.

Regardless of how providers do or do not (and can or cannot) engage with patients through PLM, the system can be used to support patient-provider communication during visits. PLM users are provided numerous "tools and tips for interacting with your provider." Most notably, patients can download and print "Doctor Visit Sheets," intended to "help you improve your discussions with your doctors," that provide summary charts and graphs based on the information a patient has entered into the system. Thus, PLM and other patient-centered health records and social
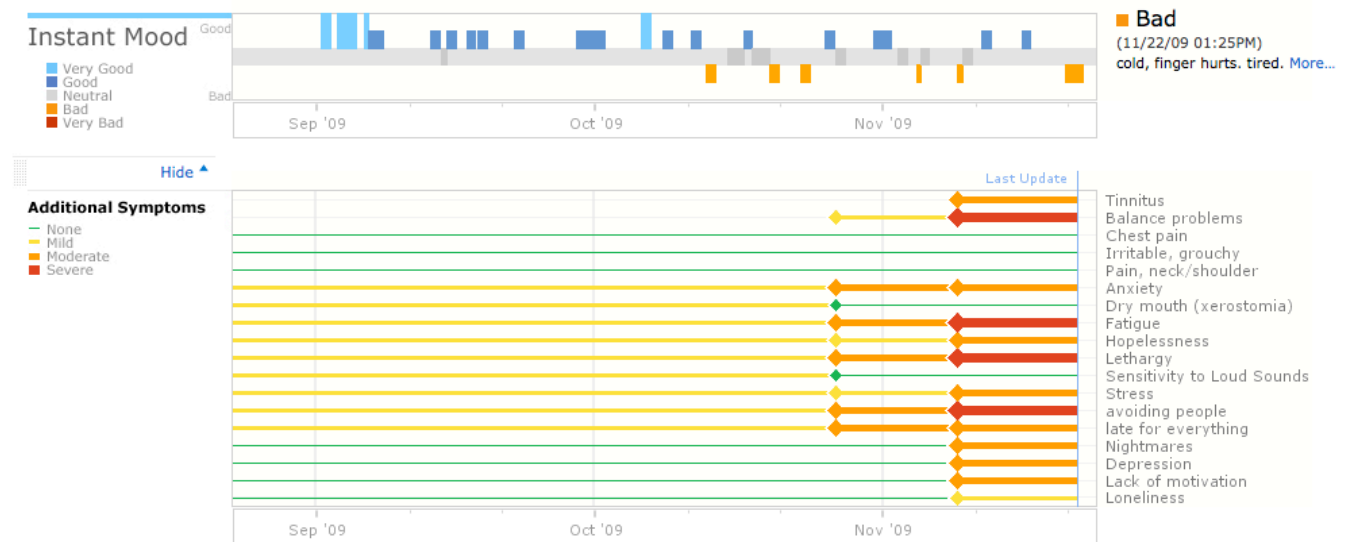
Figure 1. An example of two features in the data entry and visualization system on PatientsLikeMe. When listing symptoms, users can include custom values allowing the use of non-medical terms such as "late for everything."

network sites raise questions about the ways in which patients can contribute to their own health.

DEMANDS FOR DATA

Access to patient data is a central issue in medical research and patient care. Health information technologies are consistently touted as offering the promise of large quantities of aggregated patient data for epidemiology and research. PLM fulfills some of this promise by aggregating and selling the data of its users. However, the input of the data is largely driven by patients' desire for greater access to their own medical records and health management tools. The concerns associated with the PLM's ability to encourage patients to enter personal data that benefits clinicians, research, and pharmaceutical companies, echo canonical concerns to the design, development, and adoption of CSCW and groupware systems [6].

A primary difference for PLM from other CSCW systems and SNS, however, is the relative sensitivity of the data stored and shared. In most cases, legal restrictions that protect patient privacy also restrict the availability of data for both patients and other interests alike. PLM's solution to the issue of privacy deserves serious consideration. While the site has a detailed privacy policy, PLM focuses on their "Openness Philosophy." "[M]ost healthcare data is inaccessible due to privacy regulations or proprietary tactics..." the philosophy reads. "[W]e believe data belongs to you the patient to share with other patients, caregivers, physicians, researchers, pharmaceutical and medical device companies, and anyone else that can help make patients' lives better." By allowing users to record their own medical information, PLM may avoid many of the privacy restrictions placed on other medical records systems.

Patient information on PLM is captured through a data entry and visualization system (see Figure 1). This system serves two goals: First, it steps beyond the qualitative and narrative-based interactions in earlier patient communities and allows patients to enter and track personal health information via sophisticated charts and graphs with the goal of improving their health. As Frost and Massagli [5] note, the system is based on the premise "imagery as data" and that "through collecting, analyzing, and explaining visual data for themselves, patients can gauge the impact of daily behavior on health outcomes." Secondly, the PLM aggregates and sells data with both profit motives and the desire to advance medical research and services. The data entry system, then, must negotiate these two objectives, answering the needs of patients using the site as well as market demands for patient data.

Both research and anecdotal evidence shows ways in which PLM has been responsive to user requests. For example, the PLM system allows users to select symptoms they believe are important to track, extending to the inclusion of customized symptoms (*e.g.,* "avoiding people"; see Figure 1). This customization, however, exposes problems associated with using user-generated data. Research shows

that patients interacting with the PLM system are often unaware of relevant medical taxonomies and instead enter information using user-generated "folksonomies" [15].

These issues echo the struggles of myriad institutions, such as hospitals, which for years have been attempting to "clean" clinical data to be used for research purposes. Often, these data include narratives and other unstructured data as well as abbreviations and acronyms that can represent any number of things and only make sense in context [14]. Although humans reading these data can make sense of them easily, mining this information for research data has and continues to be a substantial natural language processing and database challenge.

Questions remain as to how PLM has been and will continue to develop relative to these institutional demands for specific sets of patient data. PLM clearly notes their policy for selling de-identified patient data: "We take the information patients share about their experience with the disease, and sell it in a blinded, aggregated and individual format to our partners (i.e., companies that are developing or selling products to patients)."

There is little research that indicates how identifiable these data actually are, making it difficult for patients to make an informed decision about these issues. Furthermore, the site goes on to note that "By selling this data and engaging our partners… [we're] helping companies accelerate the development of new solutions for patients. Our end goal is improved patient care and quality of life."

In this way, the PLM administrators position themselves in favor of "openness" and collaborative information sharing—even with corporate entities—as the way forward for improved patient care. This stance is consistent with the reasoning that openness on the part of patients with each other also improves patient care.

However, corporate and patient interests are clearly different. Mixing concepts of transparency and collaboration in patient-patient interactions with patient-corporation interactions, PLM implicitly denies the power relationships and other structural elements that make this level of cooperation unbalanced for patients. There are open questions as to how much researcher demands for structured data on topics of interest might conflict in some way with patient demands for unstructured or customized data. PLM is forced to balance the potential for future health benefits derived from clinical research and product design against the potential for health benefits patients experience through the interactions they seek on the site.

At the same time, clinicians, researchers, and product designers wishing to learn from the information on the site must deal with challenges to the validity and reliability of data from PLM. First, patients may not be accurate or regular in their self-report. Second, the subset who is willing and able to post information online is not likely representative of the whole of the patient population.

Research focused solely on this group, who are likely to be well-educated and of a high enough income bracket to have regular access to the Internet, is not equitable nor ethical in its exclusion of patients who do not fit these criteria.

Despite these concerns, PLM currently conducts its own research in an attempt to affect change. For example, in 2007, a study found that some ALS (a.k.a., "Lou Gehrig's disease") benefited from lithium as a treatment [3]. As users of the PLM ALS community became aware of the study, some began including lithium in their healthcare regimen. PLM, inviting users to share their data, has produced a interactive report that displays ALS/lithium trends using live data from the site.[1] Likewise, PLM data has, in at least one case, exposed problems in medical measurements [19].

DISCUSSION AND IMPLICATIONS

As patients and the medical industry increasingly demand data-driven patient-centered healthcare solutions, sites such as PLM raise questions about the new role of the patient and the appropriate use of his or her data. As patients increasingly take a more active role in the management of their care, we ask: What is the role of patient communities in relationship to the shifting patient/provider relationship? How should doctors understand these spaces, and when and how should they participate? Relative to patient data and visualization tools, we ask: What data best represents a patient's experience of their condition, and in what contexts are patient-entered data valid? What types of data are useful in cooperative medical behavior between both the patient and the physician as well between patients?

Perhaps the most salient aspect of PLM is the importance of peer communities and support. On PLM, patient empowerment extends to community empowerment – evidenced by PLM's increasing contributions to medical research. In achieving the goal of patient-centered care, there is an obligation to fully acknowledge the needs of these patients, not only in the visiting room, but in their everyday experiences as well. This extends from cooperative patient-provider relationships into patients' psychological relationships with their diagnoses and, as seen in many of PLM's communities, the interpersonal needs of patients as they come to terms with diseases that frequently have physical, emotional, and social ramifications in their lives.

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[1] PatientsLikeMe's report on ALS and lithium can be found at: http://www.patientslikeme.com/als_lithium

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