Blog-based applications and health information: Two case studies that illustrate important questions for Consumer Health Informatics (CHI) research

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1. Introduction

Web applications such as podcasts, wikis and online weblogs (commonly referred to as “blogs”) are currently important foci of internet research [1,2]. These types of web-based applications are one part of a larger body of communication applications that are collectively dubbed “web 2.0” and are considered to give credence to well-known claims about the democratizing nature of internet technologies [3,4]. Such applications give web users easy avenues to produce/publish and exchange information, experiences, opinions, etc. and reflect bottom-up regulation of that published information. The general body of literature on weblogs and practices of blogging, especially in the social sciences, is growing. In medical publications, however, the literature specifically on health-related blogs has been quite limited. Little attention has been devoted to understanding different types of weblogs and how they are being used by the lay public for health-related purposes. Most literature is editorial, written from the perspective of doctors who are blogging, or discusses the potential roles for blogs in educating nurses and medical students [5–10]. There is a need for more research devoted to patients’ use of these alternative avenues for managing both information and experiences with respect to their health.

Despite the lack of attention for issues related to use of these specific applications, the topic is closely related to current work on Personal Health Information Management (PHIM) and Health Information Management in the Home (HIMH). Patients are increasingly expected to play a more active role as managers in their own care. The central role...
afforded to individuals implies that they have an essential responsibility to retrieve, manage, maintain and store many different kinds of information, from different sources, using different media [11,12]. Pratt et al. [11] suggest that patients need tools that address current information gathering and sharing challenges, thereby enabling them to be more involved in their health care. Specifically, they emphasize the need to create tools that are easy to use and allow for the integration of different information/communication interfaces in one. Moen and Brennan [12] contribute to this that individually oriented resources might be more effective when informed by the contexts in which they are intended to be used.

Although health-related applications such as weblogs do not completely facilitate integration or resolve other problems addressed in the articles mentioned above, they do allow individuals to utilize public web spaces to manage and share their own (care-related) information and experiences. Individuals can connect information from different types of media or sources, and in most cases, others can respond to a given blog post, adding a communication dimension, as well. Investigating under which circumstances individuals do or do not choose to use this broadcast format could provide helpful insights into how individuals use public applications to resolve the communication difficulties to which Pratt et al. [11] refer. Under the idea of “push button publishing” (all you have to do is fill in a text box and click submit), such applications are incredibly easy for individuals in the general public to use, thereby further lowering the already-low barriers to publishing and distributing various types of information that are associated with the web. This is especially important because, with weblogs and other web 2.0 applications, the line between producers and users of information becomes blurred and individual understandings of health are configured in the process, which raises many important issues that are relevant to Consumer Health Informatics (CHI) research.

This article begins with a short literature review that distinguishes blog applications from other web formats. This is followed by a presentation of two cases where applications based on blogging technologies and explicitly directed toward health care have been introduced by organizations in The Netherlands. Both cases illustrate applications that provide both a public space where individuals can share health-related information and experiences with others and a private, password protected, space for recording personal information. The cases share a similar approach and technology, but differ with respect to user group, purpose and relative success. In the discussion, the cases are used to illustrate different ways that blogging technologies can be or are being used in practice and to point to several important questions that future CHI research on this topic should address.

2. Materials and methods

2.1. Literature review

Literature on this topic was collected at three different points during October 2006 and April 2008. The terms “second generation web,” web 2.0, wiki, weblog and blog were used singularly and in combination with the terms patient, health and medicine to search in Scopus, an Elsevier abstract and citation index which, in addition to covering Medline, also returns results from social science publications and the web. It includes access to Open Access Journals, Conference Proceedings, Trade Publications and Book Series [13]. As a secondary measure the same terms were also entered into both Medline and the advanced search form of Google Scholar [14]. The advantage of using Scopus and Google Scholar is that these also return findings from the Social Sciences, which have progressed further in research on the topic and thereby can provide additional insights.

The second and third literature searches also included the terms “health 2.0” and “medicine 2.0”, which have been coined in reference to second generation applications and changing health care roles [15,16]. All journal and news articles, conference papers, editorials, weblogs, wikis and books (or book chapters) that discussed blogging applications in general or blogging practices specifically related to health care were considered relevant to the study and were included in the review. This literature was used as a general framework for the introduction and discussion sections, as well as for Section 2, where characteristics of blogs are described.

2.2. Web analyses and interviews

Two active sites, a weight loss promotion site and a site where patients with rare diseases can record their experiences with medications, were reviewed and compared. In November 2006, an analysis was made of the first website (weight loss promotion). The layout, content and functions of the website were analyzed from a user’s perspective. The review focused on tools for information provision, communication possibilities and topics addressed both formally by the site designers and informally in discussion groups. After the analysis was made, a semi-structured interview was conducted with two of the health educators that review content and supervise users of the site. The second site was analyzed in February 2007. Because the site was password protected, information about the site was first gathered through email contact with the organization and information pamphlets. After the site was reviewed for content, layout and functions, the project leader was interviewed via both phone and e-mail.

3. Distinguishing blogs from other web-based applications

Blogs are generally defined as personal web sites with content displayed in reverse-chronological order [17]. They can deal with personal or private issues or aim to situate themselves within the public (political) discourse on a given topic [18]. New posts are placed at the top of the page instead of the bottom, making changes easily identifiable. In contrast to the generally accepted anonymous image of information on the web, blogs often have an identifiable author and include pictures or other personal information. Site visitors can usually leave comments for others to see, adding a community dimension to the blogs, whereby they also resemble bulletin boards or discussion groups. Blogs can be joined to other blogs through
hyperlinks and the global network of blogs is referred to as the “blogosphere” [17].

Weblogs are often thought of as analogous to online diaries; however, this is a misconception and the two terms should not be used interchangeably [19]. Blogs began as lists of links to (i.e.: logs of) other interesting web content but have evolved to include many different forms of multimedia content, including combinations of links, text, photographs, videos and other web materials. An important aspect of blogs is that the format and tools used to produce the blog are more defining than the content [19,20]. Bridging different media genres, whereby not only the more traditional web 1.0 applications and tools, but also older media such as film, television, radio, etc. are mixed together in one interface, is one of the important defining elements of blogs [21]. Information presentation shifts from primarily text-based information to include interactive, visual and auditory material and the different features offered by the websites discussed below transcend both different web categories (home pages, discussion boards, chat, text, video, pictures, news, opinion, experience, etc.) and broadcasting avenues (one to one, one to many, many to many, etc.).

Although it is difficult to estimate the actual number of active blogs, Technorati [22] tracks blogs and tagged social media. As of June 2008, the site is tracking 112.8 million weblogs, up from 7.8 million blogs in 2005 [5]. The organization projects that more than 175,000 new blogs are created each day [22]. How many of these are devoted to health and wellness is difficult to discern, partly because of the rapid rise of such blogs [23] and partly because the health-related information or sections of an individual blog can be implicit or explicit and identifying health-related topics within a blog is largely dependent upon how information is tagged.

3.1. Implicit and explicit health-related blogging

Information about an individual’s health care in existing personal web spaces can be implicit, explicit or a combination of the two. Implicit would refer to weblogs that consist of links to many different types of web material on more general topics, but that also refer to health-related issues or practices as part this larger body of topics and discourse on daily life. In this case, one would have to search blogs for instances of links, thoughts, or experiences related to health care. Explicit would refer to blogs that are set-up with a particular health situation in mind. An example would be coping with a chronic disease such as diabetes [24], documenting a specific (limited) trajectory such as pregnancy, or to support attempts to achieve specific health care goals, such as losing weight or smoking cessation. An example of a hybrid of these two types of health representation is the blog maintained by sociologist and internet researcher Hargittai [25]. Hargittai posts links of interest and shares personal information and experiences in journal format. The archives of her posts are tagged according to topic. The part of her blog archive explicitly tagged for “health and fitness” refers to posts about her specific goal to run a 5K marathon, while other current posts and archives reveal more implicit references to her health and well-being.

In the two case studies discussed below, blogging applications enable lay persons to engage in explicit health-related blogging practices. The first case study examines an innovative tool for supporting individuals in meeting a particular health goal—weight loss. The tool examined in the second case is much more directed toward coping with a chronic disease and disease self-management. In both cases, there is a secondary focus on the personal experience dimension of the information being produced.

4. Case 1: health promotion and weight loss

The 'Valtaf' ("is losing weight") website is provided by a commercial company, Sofit Wellness [26], which develops software and content about healthy habits, nutrition and exercise. Sofit Wellness provides Valtaf sites for both Dutch and Flemish-speaking Belgian users. The websites, which were created and developed from 2004 to 2006, provide personal spaces to individual users and include diverse automatic content-generators and social functions that support participants in the weight loss process. These commercialized spaces allow individuals to keep an online journal, collect and/or register information and utilize a variety of other educational tools and resources. They also allow registered users to communicate with fellow users through discussion boards, chat groups, or instant messaging relays on the parent site and through a comment function that allows readers to post-responses to individual journal posts in the personal spaces. This site enables users to use their individual spaces to document the process of achieving a specific health goal. In other words, individuals engage in practices of “health goal-oriented” blogging in public, commercialized spaces.

These personal spaces are interlinked with the parent website, which offers asynchronous discussion boards and real-time chat, as well as content on nutrition and weight loss, as is mentioned above. It also contains its own separate blog, which presents news and other relevant materials. Most of the content is provided by volunteers and articles are posted by both Sofit employees and selected site subscribers. All content is screened by health care consultants (a trained dietician and a trained nutrition specialist) that work full-time for the site. The parent site also has direct communication with individual users. Submission of measurements and data is supported with e-mail reminders and all participants also receive weekly newsletters. Registration on the site is free, but for a fee, users can receive more intensive, personalized supervision with one of the aforementioned health care consultants. As much of the site as possible is kept open so that individuals first have the opportunity to experience it before they register. The organization estimates that at any given time there is a constant of approximately 75 registered (but not necessarily paying) users and 75 visitors on the site. Current site records reveal that the average user is between 20 and 45 years old and 90% of the users are women.

4.1. The personal web spaces

Through their links to the parent website, the personal web pages contain more content options than are expected from online journals, but the individual pages are built, at least
partially, with the same easy-to-use functions as popular blogging websites and they include the unique combination of information formats that is common to present-day weblogs. This content distinction is due in part to the fact that the site has developed through constant communication with its users, such that all of the content types and active functions have been added, adjusted and even removed in response to user requests. In addition to submitting data about their daily food intake and exercise, weight, fat percentage, BMI, and physical measurements using a form that allows push button publishing, users can also post-personal photo’s and write journal entries with (animated) emoticons. The term emoticon refers to a graphic image that is used to indicate emotions and attitudes that would otherwise be conveyed by body language or facial expressions in face-to-face communications. The best-known emoticon is the common yellow smiley-face, which may be winking, crying, red with anger, etc. The animated emoticons on the web page in question carry out actions related to the topic of weight loss; for example, a smiley with arms and legs may be wearing exercise gear and lifting weights. Data entries are repackaged in helpful charts and graphs that track progress over time, while the journal provides a compendium for understanding the trends reflected in the graphics by providing insight into specific factors in their daily lives that may have affected eating/exercise habits.

One interesting aspect of the site is the personal nature of the information that individuals choose to display. Web-based communication is often thought of as anonymous and faceless. This is called into question with applications such as blogs, very aptly demonstrated in this case, where users generally register with a pseudonym as their user name, but their websites are not necessarily private/protected or anonymous (although they can be either or both). Introductory texts include user names and often geographic location, while their daily blog posts reveal more and more personal information over time. The photograph policy on the sites requires that any photos posted include the registered user, whereby a face is also linked to this other personal information. Users have contact with buddies they meet (mostly) through the site and they also join clubs of individuals with similar characteristics (geographic location, age group) or with similar sub-goals (following a certain diet program or remaining smoke free). Once on the site, users have an overview of newly updated sites, current online participants and each participant's individual progress. As Nardi et al. [27] have argued about blogs more generally, in these public spaces, individual practices of documenting experiences with an otherwise private and personal health issue become part of larger public processes and social activities.

5. Case 2: the digital personal experiences record

In the earliest phases of establishing websites with a national reach, one way to ensure that the content available on a given site aligned with the information that users expected to find was to study log files of user search terms. While this approach was important and even recommended, it also had a disadvantage in that it contributed to an already existing information divide [28]. When official or recommended sites directed their attention to the most popular health topics, the same topics continued to receive attention, while rare diseases and less sought after terms remained unaddressed. For groups where information is already scarce, official sites often contributed little. In The Netherlands and other European countries, the communication aspects of web applications have become more important for such groups than unidirectional information provision via, for example, a national portal. The communication options on the web offer these groups of patients opportunities to contact one another and exchange information, often with certain individuals collecting, repackaging and translating information to share with others [29].

Recognizing the need for Dutch patients with rare diseases to be able to share their experiences and communicate with one another, the Prevention and Health division of The Netherlands Organization for Applied Scientific Research (TNO) [30] partnered with 11 patient associations and health-related non-profit organizations in 2004 and created the Digital Personal Experiences Record, which was online through June, 2007. Use statistics published on the site in 2007 indicated more than 200 individual (personal) records and 170 (public) published experiences. According to site administration, use was fairly evenly divided among the genders, even though there were more women registered than men. User ages ranged from younger than 10 years old to 90 years old, with the majority of users being between 21 and 70 years old.

The website had a digital-identifier protected area that contained the individual’s actual record, as well as a public section on personal experiences with medications, physicians, etc. The organization considered the record to be an important instrument for contributing to individual patient empowerment. Although the personal record was not originally a blog, the public experiences section was based on the simple click-and-send format afforded to blogging technologies and included both an outlet for posting comments and an opportunity for others to reply. Archived comments were listed in a simple table structure, with five category headings and two icons per entry. The headings included the alias of the author, the topic, the member organization, a rubric tag (e.g.: quality of care, communication) and the article (e.g.: the name and dosage of an individual prescription for entries about medicines). The icons indicated the user’s opinion of the experience (e.g.: poor, average, great, etc.), and whether the post was about an experience with a physician or with a given medication/treatment. Although the comment function of the site worked well, there were other usability issues related to lay-out and design that made it difficult to use. For this reason, the site was deactivated in June 2007.

The record was intended to provide individuals with an easy interface for recording and overseeing their medical information and experiences. Managing information in this way would potentially enable them to have more insight into their own situation, while also having a basis of comparison with others. Furthermore, it was hoped that the records would reveal certain trends among the target populations, which would further enable the organization to respond to the specific information needs for those groups. The website further
suggested that the feedback gathered from individual contributions to the site could be used as input in the policy-making process to improve the quality of medicines and services for a given target population.

As in the first case, the individuals had control over how much information they revealed about themselves online. However, other aspects of sharing experiences differed. Whereas the first site offers more opportunities for integrating specific individual experiences and trends over time with public, social processes, this is much less the case with the Digital Personal Experiences Record. Due to the sensitive nature of the information, the publicized experiences are at least more anonymous, if not completely decoupled from the individual. Tracking changes and trends over time in this case takes place at the population, rather than individual, level, whereby it is suggested that aggregated data can be used for population-based research purposes and as input for policy change.

6. Discussion

The discourse around web 2.0 reiterates the same claims made 10 years ago about the opportunities and challenges of posting health information and resources on the web. Ramos and Piper [4] argue that these applications comprise the most current iteration of user-driven tools, resources and power, where expertise emerges from the combined efforts of many, rather than being in the hands of a few. Use of terms such as “health 2.0” carries the implicit suggestion that this generation of applications ushers in new approaches to health care. Further, it reflects expectations that these applications will fulfill promises already associated with the internet, such as increased patient independence and democratization in the health care process.

However, the quality of information being produced (primarily by lay web end-users) using different web 2.0 applications is an issue of concern [31]. The ability of the collective to correct mistakes has been called into question both generally [32] and specifically for health-related information [33]. This of course presents new challenges to those actors and organizations that work to improve the quality of information on the web and help end-users find and evaluate that information. Nonetheless, as is further discussed below, organizations also see potential in using such applications (especially blogs) to aggregate information about patient experiences and use this information for greater purposes. Network applications, thus, are still considered to be simultaneously capable of contributing to patient empowerment and endangering patients by potentially exposing them to various forms of incorrect health information [34].

Although the potential importance of, and problems with, the applications collectively known as web 2.0 is recognized, these applications (most especially health-related weblogs) with respect to health-related information are currently understudied [35]. The purpose of this paper has been to take a first look at examples of health-related blog development in The Netherlands and to raise questions about new trends in health information management that are emerging with the further development of point-and-click tools.

In both case studies, not enough information about user experiences was available to make any detailed claims about blogging for health from the patient perspective. Therefore, it is important to point out that especially this area is in much need of further study. The sections below point to several different issues that are relevant for further CHI research into health-related blogging. These are categorized into two primary subject areas: issues related to individual experiences with blogging and those related to use of blogs for the purpose of changing health policy and/or services.

6.1. Issues related to individual experiences with blogging for health

The first case study is reflective of an increasing trend toward providing a web space where individuals have more tailored resources to deal with a certain health situation, as well as to offer their own information for use by others. Especially in The Netherlands, there is a proliferation of sites devoted to tracking weight loss or another health-related goal. But this trend is also evident on English-language blogs, as seen, for example, in a recent list of top 100 health wellness blogs [23] that includes several individual attempts to track weight loss progress online. Few of the sites on this particular list, however, have the individual and community mix that is evidenced on the Valtaf site discussed above.

Because such public blogging sites are gaining recognition in the popular press [36] and because various parties are entering the field with web-based solutions for documenting health information that utilize point-and-click technologies [37–39], it is crucial to examine from a user’s perspective what aspects of these blogging tools and alternative site options are most important and why/how these are effective. This should include first identifying and categorizing health-specific blogging sites and typifying who uses different types of blogging sites, as well as why and how they use them. One can also question whether online tools are as effective as they are portrayed in popular media to be, which points to the need for both quantitative studies and qualitative studies of these applications. Gathering more information about how individuals use a given site and what they think of individual site features informs not only the design and maintenance of the site, but also understandings of how these types of sites fit into health care/information management processes.

In the first case presented here, many users keep a daily or weekly chronicle of their experiences, which is a rich source of data about how individuals construct their own (health) identities. It is important to understand how blogging as an activity fits into an individual’s past and present uses of other documentation and communication media, both in general and specifically with respect to health. How does keeping an online record of one’s progress motivate users to stick to the routines that are necessary to achieving their personal goals? What work is involved in managing information and keeping up these personal spaces? [12] If health care provider organizations can identify the target populations that are most benefited by such applications, they can explore these new avenues for reaching their own user groups for promotion and prevention purposes.
Because interactions are not limited to online instances but also reflect blending with respect to online and offline communication, another important question that deserves more attention is how web 2.0 technologies are configured within existing and new (health) networks. How do the lines between online and offline relationships shift when patients begin documenting specific health care practices for which they need support? Important in this respect is developing a further understanding of the relationship between lay and expert knowledge—how do individual users view expert opinions and advice vis-à-vis information they encounter in the blogosphere? How do patients bring information from blogs into the medical encounter?

Related to this, more research on information quality must be conducted, as well as research on how the roles of third party organizations that certify online information are changing in response to these developments. What new review practices are emerging? How are website selection policies and procedures (or conditions for use) adjusted such that they also apply to perpetually changing information, information created by lay web end-users and information that is no longer primarily text-based but that transcends different media formats?

One final issue on this topic is the comparative use of health-explicit blogs that are not designed by a company or institution for a specific target group, but created by individuals of their own initiative using popular blogging sites. Understanding how these different applications compare and why individuals choose one application over another is important because sites provided by an organization are goal-oriented in a manner more consistent with traditional ideas about health and prevention. A general personal blog that contains references to health and care experiences is potentially much more critical or radical, and thereby more reflective of the discourses and ideas revolving around “health 2.0.”

6.2. Issues related to blogs as feedback for changing policy and improving services

The second case differs from the first in that it carries the suggestion that blogs can be used to garner input for health policy and improvement of services. This particular case is currently less reflective of typical health-related uses of blogs. However, there are key examples of American and English sites [40,41] that, with quality improvement and political goals in mind, currently solicit feedback from individual patients about their experiences with one or more aspects of the care process. A recent report [42] argues that this type of feedback regarding providers and treatments is developing into an online system that generates transparency in the health system.

In such cases, information “management” becomes a broader concept. Existing research approaches the patient’s managerial role as an issue of individual information management, with (often top-down) practical projects set up to address information sharing challenges and integration of different interfaces [11,43]. The approach of the second case presented here, however, suggests that these applications can be more than just personal web spaces. As health care organizations become more interested in collecting qualitative data on patient experiences and engaging their patients in a dialogue about quality improvement, they can follow changing trends in business practice and establish blogs as (bottom-up) tools for customer relations [17,42].

The patient’s role, thus, extends beyond managing information only for individual health. Where blogs are used for purposes of quality control or input for policy change, the application users (target groups of patients) become information producers, changing their current roles and creating room for new information users to emerge. Patient peers and health care providers are the expected information users, but blogs also provide opportunities for policy makers, insurers, health-related businesses and other actors to gather information about patient experiences that is not mediated by, for example, researchers. The expectation is that this information can be placed alongside other forms of information as part of a body of evidence that is used for healthcare decision-making. However, this is not unproblematic and leads to questions of whether personal experience information can feasibly be transferred to a different context [44] and whether lay expertise will be regarded on equal footing with expertise coming from other stakeholders [45,46].

One important concern about gathering data in this way has been raised in the field of Internet research, which questions whether individuals can distinguish the so-called externalities of the network. In the shift from an environment of anonymity that was often associated with the web a decade ago to a web environment where individuals voluntarily post more and more personal information, are these individuals aware of where this newly provided information is going and whether or not their interests are being protected? “Users of Web 2.0 are encouraged to put as much of their lives as possible online, to divulge and share their personal lives through blogs or on LiveJournal, their professional development on LinkedIn, share bookmarks of favourite Web sites on del.icio.us, upload the music they listen to on last.fm, detail their friendships on Facebook and MySpace, share their appointments and social events on UpComing, where they are traveling on Dopplr, where they’ve connected to wifi on Pflazer, to name just a few” [47]. Similar concerns about the abundance of personal information being shared on health sites have been highlighted in the popular press, with a recent article discussing the surprising availability of otherwise private information, such as addresses and telephone numbers, on the highly publicized website, PatientsLikeMe [36,37]. Issues of data security – what data is being collected, how it is stored, and whether or not further use of data is clear to the site’s end-users – are of special concern. These concerns are also linked to issues of privacy and the ethics of profiling and surveillance that accompany aggregating information as input for policy and services.

Even when information is given voluntarily, it is important that individuals understand how it will be used. Despite such concerns, given the increasing interest among health care organizations in gathering qualitative data on patient experiences, the feasibility of using blogging tools to this end, and how to address related ethical issues, should be further researched.
7. Conclusion

In many respects, the ideas discussed here are not new: certain categories of patients have been encouraged to keep diaries for years and recent research has studied the effectiveness of online discussion boards and other web-based tools. Nonetheless, new and emergent tools and applications that are available via the still very much changing internet are of special importance. There are many options available and the numbers continue to grow as different types of organizations attempt to establish a position with respect to existing health care institutions. The uniqueness of blogging applications is found in the blending of many different tools together in a single interface where information creation, retrieval and management are not only made easier, but also combined with interactive communication with both peer and expert contacts.

In this paper I have used two case studies to identify several important questions that can be raised about these new combinations and applications. On the one hand, when looking at personal information documentation, these two examples reflect more traditional ideas of health care and the expected roles of patients, whereby they do not necessarily reflect the ideals associated with web 2.0 and the rhetoric of “health 2.0.” On the other hand, they do point to opportunities for enabling patients to be more active in documenting and managing information related to their health experiences, which can be used for a variety of different purposes, some of which potentially reflect those ideals.

What can we learn from the fact that patients are taking it upon themselves to utilize these and other publicly available applications for health purposes? Research into health-explicit blogging practices among patients will increase our understanding of how alternative avenues for managing health information foster healthy practices and contribute to patient identities and understandings of health. Understanding what tools patients want and how they use them will also enable health care providers to capitalize on these easy-to-use applications for patient education, disease prevention and health promotion, or for changing policy and improving services.

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