Journal of Medical Internet Research

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Editorial

Medicine 2.0: Social Networking, Collaboration, Participation, Apomediation, and Openness

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Abstract

In a very significant development for eHealth, a broad adoption of Web 2.0 technologies and approaches coincides with the more recent emergence of Personal Health Application Platforms and Personally Controlled Health Records such as Google Health, Microsoft HealthVault, and Dossia. "Medicine 2.0" applications, services, and tools are defined as Web-based services for health care consumers, caregivers, patients, health professionals, and biomedical researchers, that use Web 2.0 technologies and/or semantic web and virtual reality approaches to enable and facilitate specifically 1) social networking, 2) participation, 3) apomediation, 4) openness, and 5) collaboration, within and between these user groups. The Journal of Medical Internet Research (JMIR) publishes a Medicine 2.0 theme issue and sponsors a conference on "How Social Networking and Web 2.0 changes Health, Health Care, Medicine, and Biomedical Research", to stimulate and encourage research in these five areas.

JMIR's Theme Issue and Conference on Medicine 2.0

In the past 9 years, the *Journal of Medical Internet Research* (JMIR) has been publishing hundreds of research and opinion articles on how the Internet is changing medical practice, transforming biomedical research, and empowering health care consumers. While we have seen many new concepts and terms appear and disappear, the term "Web 2.0" (and its derivatives, for example "Web 3.0") is increasingly entering our discussions and is likely here to stay.

It is easy to dismiss some of the "hype" around Web 2.0 as a marketing gimmick or rhetoric geared towards attracting venture capital for Web 2.0 startups. However, most Internet researchers and developers probably also agree that recent advances in web technologies and user interfaces have greatly changed the design, appearance, stickiness, and pervasiveness of Web applications, and in many cases transformed the way users interact with them. Perhaps equally importantly, it also has changed the *expectations*

of users. After some hard lessons learned from failed Web ventures which disappeared overnight taking any user-generated data with them, people expect Web applications to be open and interoperable. Improved communication between separate software applications ("mashups") via open Web standards leads to improved collaboration and communication across applications. Social networking approaches revolutionize the way people collaborate, identify potential collaborators or friends, communicate with each other, and identify information that is relevant for them. And finally, Web 2.0 technologies such as AJAX lead to improved Web interfaces that mimic the real-time responsiveness of desktop applications within a browser window. Semantic Web applications (sometimes called Web 3.0) and 3D environments (such as Second Life) can also be seen as second generation Web technologies.

The emergence and broad adoption of Web 2.0 technologies and approaches coincides with the more recent emergence of Personal Health Application (PHA) Platforms (also called Personally Controlled Health Record [PCHR] platforms or "health record banks") such as Google Health, Microsoft

HealthVault, and Dossia, where data is—at the request of the consumer—pulled from various sources (including electronic health records). As eloquently argued by Mandl and colleagues in the *New England Journal of Medicine*, these developments represent "tectonic shifts in the health information economy" [1] with far-reaching consequences for patient involvement, as the gravity shifts away from health care providers as the sole custodian of medical data. PHA (or PCHR) platforms, "where health care consumers independently decide about subsequent disclosure [of health data]" represent nothing short of a "disruptive innovation that inverts the current approach to medical records in that they are created by and reside with patients who grant permission for their use to institutions, clinicians, researchers, public health agencies, and other users of medical information" [1]. A randomized controlled trial with the PCHR system Dossia illustrates the potential of PCHR for public health [2].

It easy to imagine that the combination of both trends—Personal Health Records combined with social networking, what I have called "PHR 2.0" [3]—may lead to a powerful new generation of health applications, where people share parts of their electronic health records with other consumers and "crowdsource" the collective wisdom of other patients and professionals. Advances in genetic medicine will further personalize and tailor health information, based on data stored in personal health records.

Finally, we are seeing developments in biomedical research ("Science 2.0") and scholarly publishing which apply the same principles of participation and collaboration across different points along the continuum of knowledge production and dissemination.

In an attempt to foster and stimulate research in these areas, JMIR is proud to sponsor the new Medicine 2.0 congress series [4,5] and to publish this theme issue on "How Social Networking and Web 2.0 changes Health, Health Care, Medicine and Biomedical Research".

On the Scope and Definition of Medicine 2.0

While it may be too early to come up with an absolute definition of Medicine 2.0 or Health 2.0, Figure 1 shows a suggested framework, created in the context of a call for papers for the purpose of scoping the Medicine 2.0 congress and this theme issue [5]. The program of the first Medicine 2.0 conference [6] also gives a good idea of what academics feel is relevant to the field. An explanation of why we chose the title "Medicine 2.0" over "Health 2.0" has been given elsewhere [4]; it suffices to say at this point that most authors do not necessarily see a significant difference between Health 2.0 and Medicine 2.0 [7]—if anything, Medicine 2.0 is the broader concept and umbrella term which includes consumer-directed "medicine" or Health 2.0.

According to the model depicted in Figure 1, five major aspects (ideas, themes) emerge from Web 2.0 in health, health care, medicine, and science, which will outlive the specific tools and services offered. These emerging and recurring themes are (as displayed in the center of Figure 1):

1) Social Networking,

2) Participation,

3) Apomediation,

4) Collaboration, and

5) Openness.

Figure 1. Medicine 2.0 Map (with some current exemplary applications and services)
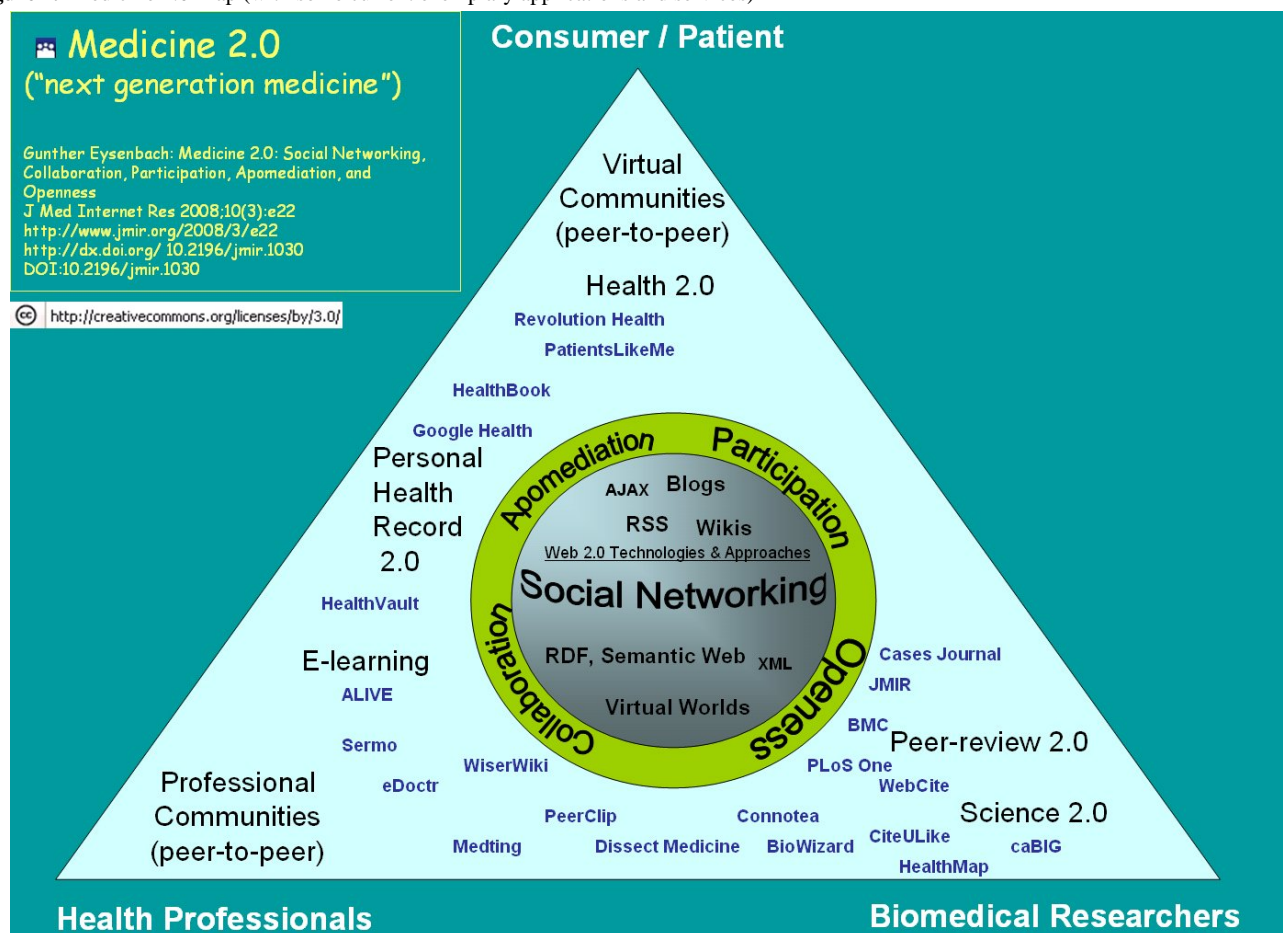
While "Web 2.0", "Medicine 2.0", and "Health 2.0" are terms that should probably be avoided in academic discourse, any discussion and evaluations concerning the impact and effectiveness of Web 2.0 technologies should be framed around these themes. Each of the 5 themes will be considered in detail below.

Figure 1 also depicts the three main user groups of current Medicine 2.0 applications as a triangle: consumers/patients, health professionals, and biomedical researchers. While each of these user groups have received a different level of "formal" training, even end users (consumer, patients) can be seen as experts and—according to the Web 2.0 philosophy—their collective wisdom can and should be harnessed: "the health professional is an expert in identifying disease, while the patient is an expert in experiencing it" [8].

Current Medicine 2.0 applications can be situated somewhere in this triangle space, usually at one of the corners of the triangle, depending on which user group they are primarily targeting. However, the ideal Medicine 2.0 application would actually try to connect different user groups and foster collaboration between different user groups (for example, engaging the public in the biomedical research process), and thus move more towards the center of the triangle.

Putting it all together, the original definition of Medicine 2.0—as originally proposed in the context of soliciting submissions for the theme issue and the conference—was as follows [5]:

Medicine 2.0 applications, services and tools are Web-based services for health care consumers, caregivers, patients, health professionals, and biomedical researchers, that use Web 2.0 technologies and/or semantic web and virtual-reality tools, to enable and facilitate specifically social networking, participation, apomediation, collaboration, and openness within and between these user groups.

Interestingly, Benjamin Hughes' extensive literature review published in this issue concludes with a very similar definition [7].

There is however also a broader idea behind Medicine 2.0 or "second generation medicine": the notion that healthcare systems need to move away from hospital-based medicine, focus on promoting health, provide healthcare in people's own homes, and empower consumers to take responsibility for their own health—much in line with what others and I have previously written about the field of consumer health informatics [9] (of which many Medicine 2.0 applications are prime examples). Thus, in this broader sense, Medicine 2.0 also stands for a new, better health system, which emphasizes collaboration, participation, apomediation, and openness, as opposed to the traditional, hierarchical, closed structures within health care and medicine.
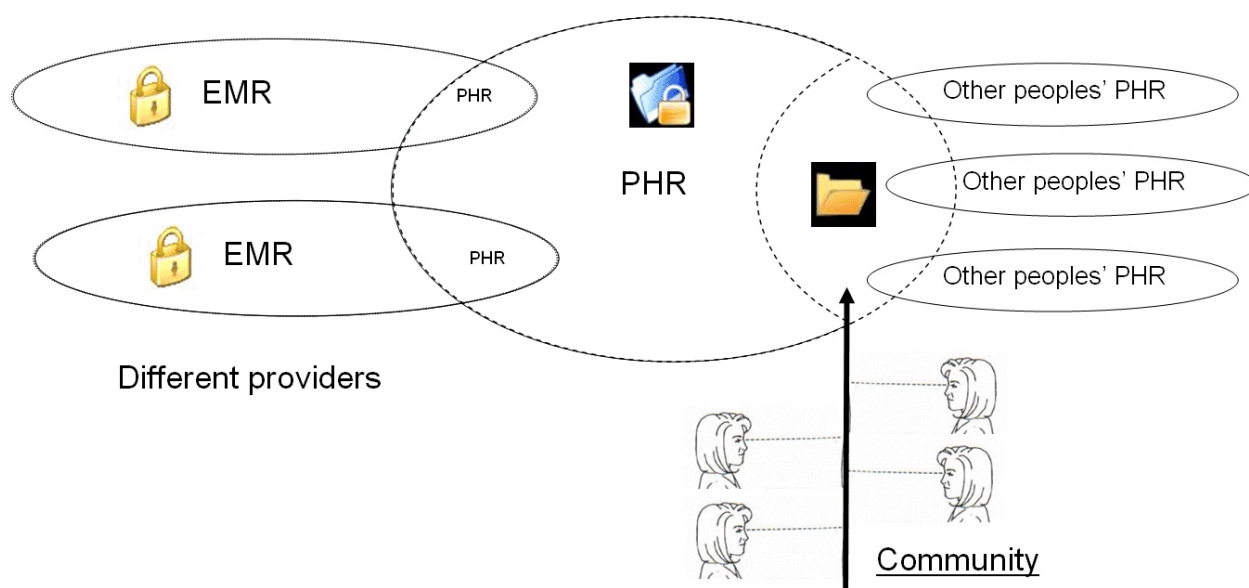
Social Networking

Social networking is central to many Web 2.0 and Medicine 2.0 applications and involves the explicit modeling of connections between people, forming a complex network of relations, which in turn enables and facilitates collaboration and collaborative filtering processes. For example, it enables users to see what their peers or others with a predefined relationship ("friends", "colleagues", "fellow patients" etc.) are doing; enables automated selection of "relevant" information (based on what peers are doing and reading on the Web); enables reputation and trust management, accountability and quality control, and fosters viral dissemination of information and applications (it is this "viral marketing" aspect that makes Web 2.0 applications so attractive to venture capitalists and public health practitioners alike). Moreover, social networking is a potentially powerful tool to engage users, in that it provides "social" incentives to enter, update, and manage personal information. Teenagers spend hours keeping their Facebook profile current, constantly updating their status. Now imagine the same generation of users turning their attention and energy to similar tools for health (what I called a "Healthbook" application). Will social networking be the killer application

that gets people interested in personal health records, motivates users to take responsibility for their health and health information, and—more importantly—retain their interest over time? Will these mechanisms help to combat the "Law of Attrition" [10], ie, the phenomenon that many patients lose interest and stop using online health applications after some time?

I predict that this will be a very active and interesting area of research. The social networking idea, which involves modeling relationships between actors, is a relatively new idea in health informatics. For example, what is traditionally "modeled" in electronic health records is usually medical information (symptoms, diagnosis, therapy), but not relationships between people. True, in most electronic health records we usually have some database fields for storing the name of the family physician, the attending physician, closest relatives and emergency contacts, and perhaps a narrative free text social anamnesis, but none of the existing health record systems support the explicit modeling of the patients' or health professionals' complex social network. When we combine social networking approaches with emerging technologies such as Personal Health Records, a new class of applications emerges—PHR 2.0 [3] (Figure 2).

Figure 2. PHR 2.0: Conceptual model of a second generation of personal health records, which not only allows patients to access their electronic health record, but to share parts of it with other people, building communities around certain health topics and issues.

For quality management and collaborative filtering, the application of social networking (and the attempt to model relationships) is not an entirely new idea. In fact, almost a decade ago, within the framework of the MedCertain and MedCircle projects, we started thinking about this and envisioned the explicit modeling of social relationships and information concerning "who said what about a specific website" as one promising way to guide consumers to high-quality information. We developed a vocabulary to describe relationships between those involved in quality initiatives on the Web, with the eventual goal being to build intelligent tools

that can harness this information [11]. Today, this approach might be called a Web 3.0 application (which is a bit misleading, as the relevant technologies such as semantic web, RDF [resource description framework], FOAF [friend-of-a-friend] etc. pre-date most Web 2.0 technologies). Today we would probably rely on a folksonomy, rather than trying to develop a taxonomy.

Participation

Participation is another central theme and core value in Medicine 2.0. This aspect is particularly important for consumers and patients but also extends to health professionals and researchers. Personal Health Records and, in particular, PHR 2.0 [3] are a part of this development. Over the past decade we have come a long way toward this goal of consumer participation in health care. When I first wrote about the promise of consumer health informatics opening up the possibility for consumers to access their electronic health record [9], this way of thinking was far from mainstream, and not many people thought this was a realistic or even desirable goal. But the Web and related technologies have changed attitudes and the culture in health care. The Internet has been a tool for users and citizens to get more involved and empowered, and Web 2.0 tools take this to a new level, as the philosophy of end-user participation and engagement ("trust your users") is deeply ingrained in Web 2.0 thinking, exemplified by tools like wikis.

Wikis are the perfect example to illustrate that the "participation" theme is also relevant for other user groups, such as scientists or health professionals, and can be adopted for tasks like scholarly communication.

There is another aspect of Web 2.0 and Personal Health Records/Personal Health Application Platforms which excites consumers and researchers alike: These platforms provide—at least theoretically—unique opportunities to address directly the concerns of patients regarding secondary use of their data for research, and to facilitate obtaining informed consent for participation and data use in research studies in an ethical manner. For example, most patients do not want "the obtaining of consent [to participate in a research study] to detract from the reason for their appointment. They expected their health, not research, to be the focus of the consultation" [12]. PCHR platforms allow consumers to access and control their personal health information and provide the possibility to obtain consent in a different setting than during a clinical consultation: through the Internet, where it is contextualized by educational information. It can even be argued that *patient-access to their own data is a prerequisite for engaging the public*. As Mandl and colleagues argued: "Patients should be able to grant or deny study access to selected personal medical data. […] All these patient functions should be accessible from any web browser in the world." [13]

In summary, the emergence of social networking platforms and applications such as Facebook or PatientsLikeMe [14], potentially combined with "PHR 2.0"—personal health records which allow users to share parts of their electronic health record with other users—create new levels of patient participation, as well as unique and unprecedented opportunities for engaging patients in their health, health care, and health research, and for connecting patients with informal and formal caregivers, health professionals, and researchers. However, it also creates complex privacy issues. For example, consumers—perceiving information they post or disclose on the Internet as ephemeral—may be unaware of the fact that web-information is often permanently archived and may be accessible long-term (eg, by future

employers). Little is known about the actual consumer awareness of these privacy and "persistence" issues, in particular when it comes to young participating users [15].

Apomediation

Apomediation is a new socio-technological term that was coined to avoid the term "Web 2.0" in the scholarly debate [16,17]. It characterizes the "third way" for users to identify trustworthy and credible information and services. The first possible approach is to use intermediaries (ie, middlemen or "gatekeepers"), for example health professionals giving "relevant" information to a patient. Trusted Web portals containing only information vetted by experts can also be seen as an intermediary. The second possibility is to bypass "middlemen" completely, which is commonly referred to as disintermediation. Examples are patients searching for information on the web, or travelers booking their flights directly on the booking system of an airline, bypassing travel agents. The third way, prevalent in the age of Web 2.0, is a special form of disintermediation: an information seeking strategy where people rely less on traditional experts and authorities as gatekeepers, but instead receive "guidance" from apomediaries, ie, networked collaborative filtering processes [16,17]. The difference between an intermediary and an apomediary is that an intermediary stands "in between" (latin: inter- means "in between") the consumer and information, meaning that he is a necessary mediating agent to receive the information in the first place. As a result, the credibility and quality of the intermediary heavily determines the credibility and quality of the information a consumer receives. In contrast, apomediation means that there are agents (people, tools) which "stand by" (latin: apo- means separate, detached, away from) to guide a consumer to high quality information and services without being a prerequisite to obtain that information or service in the first place, and with limited individual power to alter or select the information that is being brokered. While these distinctions are not absolute (in practice, there may be a mix of both and people move back and forth between apomediation and intermediation models), it has been hypothesized that they influence how people judge credibility, as elaborated in more detail elsewhere [16].

In the health context, disintermediation (cutting out the middleman) means more direct access of consumers to their personal data (eg, in web accessible electronic health records—upper left circle of Figure 3) and general medical information (on the web—upper right circle of Figure 3). The traditional role of the middleman is to guide consumers to relevant and credible information (the intersection of both circles in the center of the diagram). Thus, the main problem of bypassing the middleman is that consumers may "get lost" in the vast amount of information and arrive at the wrong or irrelevant information (dotted arrows). Apomediation theory conceptualizes that "apomediaries" (which includes Web 2.0 approaches) can partly take over the role of the intermediary and "push" or "guide" users to relevant and accurate information (dashed arrows).

The Web 2.0 environment is essentially an "apomediated environment", meaning that all the issues related to the

apomediation model, summarized in Table 1 [16], are relevant   for Web 2.0 and Medicine 2.0.

Figure 3. Apomediation in the health care field from the perspective of a patient.
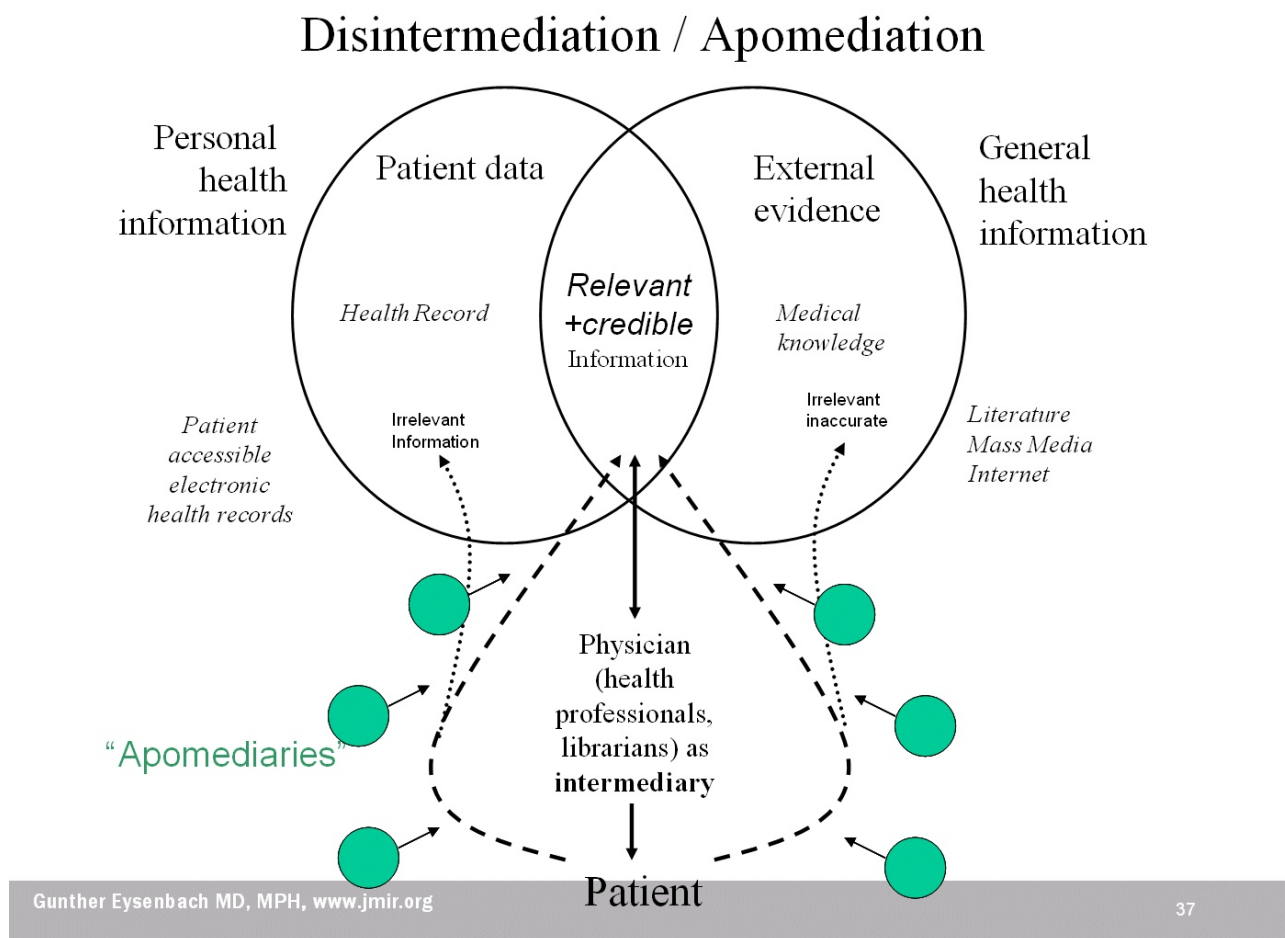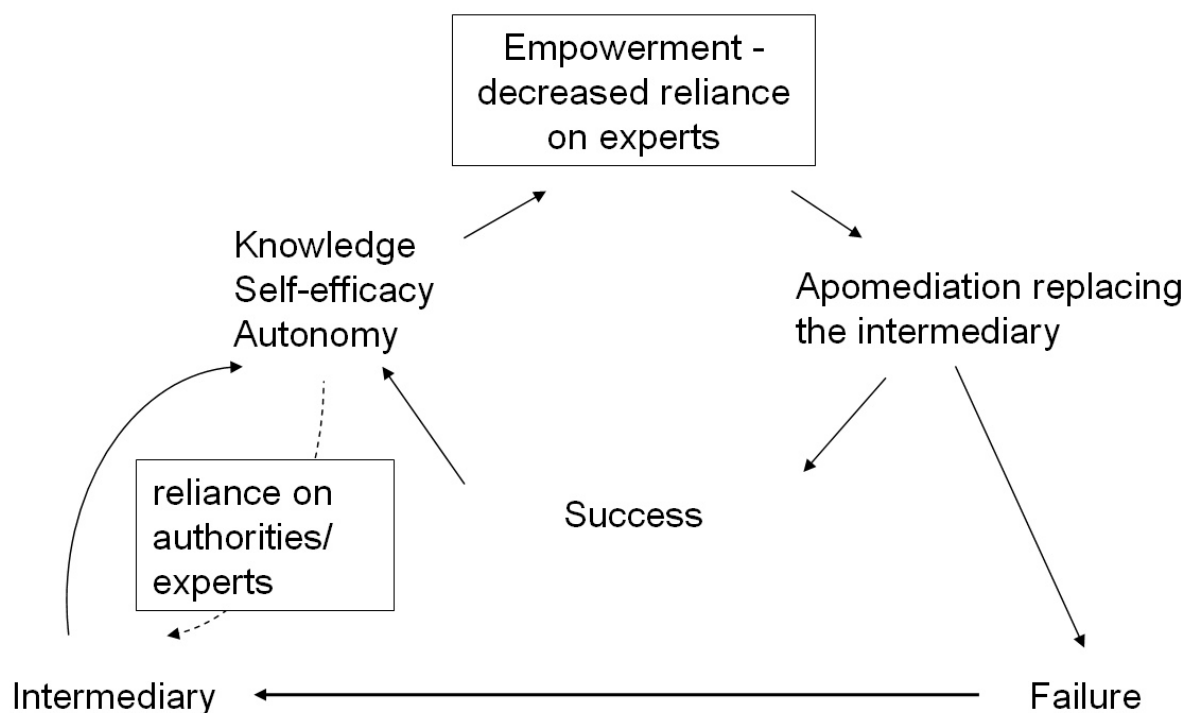
Disintermediation / Apomediation

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Table 1. Issues in an apomediation vs intermediation environment [16].

Dimension	Intermediation Environment	Disintermediation/Apomediation Environment
Overarching Issues		
Environment	Managed	Autonomous
Power	Centralized; power held by intermediaries (experts, authorities)	Decentralized; empowerment of information seekers
Dependence	Information seekers dependent on intermediaries (physicians, parents); intermediaries are *necessary*	Information seekers are emancipated from intermediaries as apomediaries (peers, technology) provide *guidance;* apomediaries are *optional*
Nature of Information Consumption	Consumers tend to be passive receivers of information	Consumers are "prosumers" (ie,, co-producers of information)
Nature of Interaction	Traditional 1:1 interaction between intermediary and information seeker	Complex individual- and group-based interactions in a networked environment
Information Filtering	"Upstream" filtering with top-down quality assurance mechanisms	"Downstream filtering" with bottom-up quality assurance mechanisms
Learning	More formal; learning through consumption of information	More informal; learning through participation, application, and information production
Cognitive Elaboration	Lower cognitive elaboration required by information receivers	Higher elaboration required by information seekers; higher cognitive load unless assistance through intelligent tools
User	More suitable for and/or desired by preadolescents, inexperienced or less information literate consumers, or patients with acute illness	More suitable for and/or desired by older adolescents and adults, experienced or information literate consumers, or patients with chronic conditions
Credibility Issues		
Expertise	Based on traditional credentials (eg, seniority, professional degrees)	Based on first-hand experience or that of peers
Bias	May promote facts over opinion, but opportunity for intermediary to introduce biases	May bestow more credibility to opinions rather than facts
Source Credibility	Based on the believability of the source's authority; source credibility is more important than message credibility	Based on believability of apomediaries; message credibility and credibility of apomediaries are more important than source credibility
Message Credibility	Based on professional and precise language, comprehensiveness, use of citations, etc.	Based on understandable language, knowing or having experienced issues personally
Credibility Hubs	Static (experts)	Dynamic (opinion leaders)
Credibility Evaluations	Binary	Spectral

Apomediation theory argues that apomediaries, such as users and friends in the case of Digg, can help users navigate through the onslaught of information afforded by networked digital media, providing additional credibility cues and supplying further metainformation. Other examples of apomediaries and apomediation tools include consumer ratings on amazon.com or epinions.com; technologies like PICS or MedPICS labels and its RDF successors that enable machine-processable dissemination and interpretation of user ratings [18]; collaborative filtering and recommender systems as exemplified by StumbleUpon.com; and other second generation Internet-based services and tools that let people collaborate on a massive scale and share information online in new ways,

including social networking sites, social bookmarking, blogs, wikis, communication tools, and folksonomies.

The Dynamic Intermediation-Disintermiation-Apomediation model (DIDA) (illustrated in Figure 4) argues that whether or not consumers prefer an apomediation or intermediation environment is highly situation-specific, and key variables in determining consumer preference for apomediation are autonomy, self-efficacy, and knowledge in a specific area for which information or support is sought. For example, a cancer patient may initially prefer an intermediary to satisfy his information needs, but with growing autonomy, self-efficacy, and knowledge, the same patient may later prefer Web 2.0 approaches to guide him to information deemed trustworthy.

Figure 4. Dynamic Intermediation-Disintermiation-Apomediation model (DIDA) [16].

Apomediation is not only important to the consumer as end user and the health professional as former intermediary. Both health professionals and scientists themselves are also switching from intermediaries to apomediaries. For example, two decades ago, researchers and health professionals still used intermediaries such as information brokers to conduct a Medline search for them, but then disintermediation took over, and they were able to search in PubMed directly. Today, these tools are complemented by "apomediaries", for example shared bookmarking tools such as CiteULike, Connotea, or WebCite, where people receive pointers to recently published relevant literature based on what others with a similar profile and interests have cited or bookmarked.

In science, we are also witnessing an apomediation process (sometimes called "Science 2.0"), with changing roles for the former intermediaries such as journals and professional publishers. Much of the communication between scientists now takes place on the Web before an article is actually published [19]. This onslaught of information necessitates the use of "apomediaries" (such as shared bookmarks) to guide users to relevant information on the Web. One can also predict that journals themselves will experiment increasingly with peer-review models that rely more on networked, bottom-up review processes, as opposed to relying on traditional "expert" peer-reviewers. Such models are not without challenges and require a cultural shift as well as strong incentives. Nature's recent open peer-review experiment suggests that most researchers "are too busy, and lack sufficient career incentive, to venture onto a venue such as *Nature*'s website and post public, critical assessments of their peers' work" [20]).

These apparent failures highlight the problem that—as has been previously pointed out [16]—what works for the entertainment industry, namely rating tools for users to rate movies, music,

etc., may not necessarily work in the medical or scientific field. Productivity tools (including health applications) have to pass a different hurdle than "fun" applications such as Facebook – they have to be trustworthy, secure and people have to see an (immediate) benefit. There is the question of incentives for users to participate and to contribute constructively to a virtual community. Social networking sites such as Facebook or Myspace work because for young people it is important to be visible, and there is a considerable social and peer pressure for youth to have a presence and a positive "karma" or reputation on such sites, so much so that there is a grey market for users to "buy" virtual friends [21]. This of course highlights another problem – which is that even networked "apomediation" models are liable to fraud and "Scam 2.0". It is an open research question whether, and under which circumstances, apomediation models work better than intermediation approaches, and how apomediation models can be made less susceptible to fraud.

Collaboration

Collaboration specifically means to connect groups of people with each other who have not, or have insufficiently, interacted with each other. In the "researcher" corner of the Medicine 2.0 triangle, this may refer to bringing together scientists using tools and approaches such as the ones described by Schleyer [22] or Falkman [23] in this theme issue. But it also involves encouraging collaboration between diverse user groups, including for example fostering public participation and engagement in research issues, and user engagement in health care decisions. Collaboration between researchers on one hand, and the public or health professionals on the other hand, also means improved possibilities for knowledge translation and getting research findings into practice.

Openness

Finally, I would argue that openness is another important and emerging theme to consider in the Web 2.0 context. On one level—the technical level—Web 2.0 stands for transparency, interoperability, open source, and open interfaces: "Don't lock me in", "my data belongs to me", "web as operating system", and "open up your API" are popular philosophies associated with Web 2.0. Personal Health Application platforms such as HealthVault and Google Health both have APIs for other applications to connect to.

What is perhaps most significant about this development is that the "openness" philosophy of Web 2.0 tools will also raise the expectations of the Facebook generation in terms of dealing with their health data. Web 2.0 savvy consumers will push the envelope and demand more than just an institutions-specific "portal" (also called "tethered PHR") which allows them to view or access their data but not to do anything else with it. Patients 2.0 will demand full control over their data (as a minimum, XML export!). Many current Medicine 2.0 applications fall short in that regard, in that people can feed information into the system but can't get it out again.

On another—societal—level, Medicine 2.0 also implies openness and transparency which enables access to other kinds of information and data the public has historically had limited access to, for example research and research data (open access journals, open data etc.), and which even allows the public to engage in the research process itself (open peer-review).

Conclusion

Openness being a key theme in Web 2.0, it is very appropriate that the *Journal of Medical Internet Research*—an open access journal—sponsors the first conference and publishes the first theme issue on Medicine 2.0. Regardless of what labels we attach to this emerging field, those interested in collaborative tools and empowerment of end users will find stimulating new perspectives for research and policy in both the conference and this theme issue. We also do not see this as a one-time event, as JMIR will continue to consider and publish submissions which fall into this area, and the Medicine 2.0 Congress is likely to be an annual event focusing on the latest technologies and societal developments to support the five themes. In analogy to what Tim Berners-Lee once said about Web 2.0—that it was "what the Web was supposed to be all along" [24])—we could also say that "Medicine 2.0 is what ehealth was supposed to be all along", and fostering and encouraging these developments was why this journal was created in the first place.

Conflicts of Interest

The author is editor and publisher of JMIR, organizer of the Medicine 2.0 conference series, and is involved in several commercial and non-commercial projects which can be called Web 2.0 or Web 3.0 applications. He is also owner of the Medicine 2.0® Congress trademark.
Note: An early draft of this article was published as a blog entry [5].

Multimedia Appendix

Figure 5. Medicine 2.0 Proceedings: Cover page
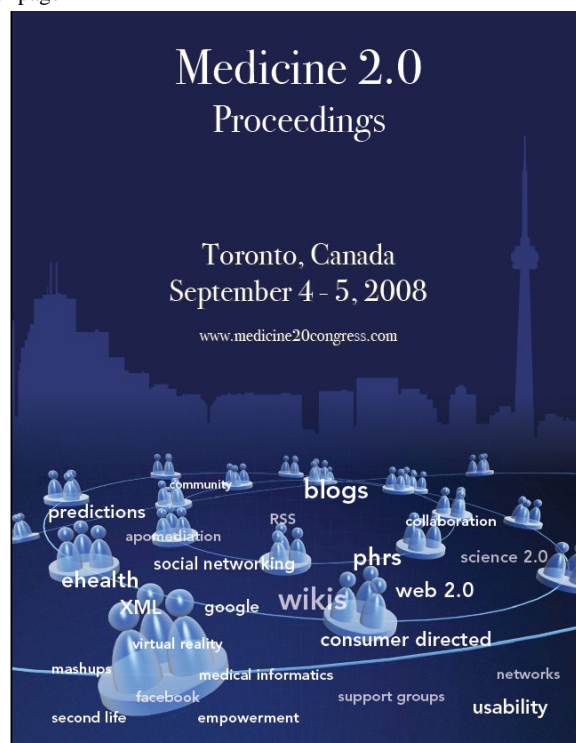
Eysenbach G (ed.). Medicine 2.0 Proceedings. Toronto, ON, Canada, Sept 4-5, 2008 [Full text PDF]

[PDF file (Adobe Acrobat File), 605 kB - jmir_v10i3e22_app1.pdf]

References

1. Mandl KD, Kohane IS. Tectonic shifts in the health information economy. N Engl J Med 2008 Apr 17;358(16):1732-1737. [Medline: 18420506] [doi: 10.1056/NEJMsb0800220]

2. Bourgeois FT, Simons WW, Olson K, Brownstein JS, Mandl KD. Evaluation of influenza prevention in the workplace using a personally controlled health record: randomized controlled trial. J Med Internet Res 2008;10(1):e5 [FREE Full text] [Medline: 18343794] [doi: 10.2196/jmir.984]

3. Eysenbach G. Google Health starts pilot test at Cleveland Clinic - and my reflections on Personal Health Records 2.0 (PHR 2.0). Gunther Eysenbach Random Research Rants Blog. 2008 Feb 21. URL: http://gunther-eysenbach.blogspot.com [WebCite Cache ID 5WAZNYYli]

4. Eysenbach G. Medicine 2.0 Congress Website. URL: http://www.medicine20congress.com/ [WebCite Cache ID 5aJsnNo4C]

5. Eysenbach G. Medicine 2.0 Congress Website launched (and: Definition of Medicine 2.0 / Health 2.0). Gunther Eysenbach Random Research Rants Blog. 2008 Mar 06. URL: http://gunther-eysenbach.blogspot.com/2008/03/medicine-20-congress-website-launched.html [WebCite Cache ID 5aLi7UZUh]

6. Eysenbach G. Medicine 2.0 Final Program. Medicine 2.0 Congress. URL: http://www.medicine20congress.com/ocs/schedule.php [WebCite Cache ID 5aJtU3rUj]

7. Hughes B, Joshi I, Wareham J. Health 2.0 and Medicine 2.0: tensions and controversies in the field. J Med Internet Res 2008;10(3):e23 [FREE Full text] [Medline: 18682374] [doi: 10.2196/jmir.1056]

8. Davidson KP, Pennebaker JW. Virtual narratives: Illness representations in on-line support groups. In: Petrie KJ, Weinman JA, editors. Perceptions of Health and Illness. Amsterdam: Harwood Academic Publishers; 1997:463-486.

9. Eysenbach G. Consumer health informatics. BMJ 2000 Jun 24;320(7251):1713-1716. [Medline: 10864552]

10. Eysenbach G. The law of attrition. J Med Internet Res 2005 Mar 31;7(1):e11 [FREE Full text] [Medline: 15829473] [doi: 10.2196/jmir.7.1.e11]

11. Eysenbach G. An ontology of quality initiatives and a model for decentralized, collaborative quality management on the (semantic) World-Wide-Web. J Med Internet Res 2001 Dec 31;3(4):E34 [FREE Full text] [Medline: 11772549] [doi: 10.2196/jmir.3.4.e34]

12. Willison DJ, Keshavjee K, Nair K, Goldsmith C, Holbrook AM; Computerization of Medical Practices for the Enhancement of Therapeutic Effectiveness investigators. Patients' consent preferences for research uses of information in electronic medical records: interview and survey data. BMJ 2003 Feb 15;326(7385):373 [FREE Full text] [Medline: 12586673] [doi: 10.1136/bmj.326.7385.373]

13. Mandl KD, Szolovits P, Kohane IS. Public standards and patients' control: how to keep electronic medical records accessible but private. BMJ 2001 Feb 3;322(7281):283-287 [FREE Full text] [Medline: 11157533] [doi: 10.1136/bmj.322.7281.283]

14. Frost JH, Massagli MP. Social uses of personal health information within PatientsLikeMe, an online patient community: what can happen when patients have access to one another's data. J Med Internet Res 2008;10(3):e15 [FREE Full text] [Medline: 18504244] [doi: 10.2196/jmir.1053]

15. Heverly RA. Growing Up Digital: Control and the Pieces of a Digital Life. McPherson T, ed. Digital Youth, Innovation, and the Unexpected. The John D and Catherine T MacArthur Foundation Series on Digital Media and Learning Cambridge, MA: MIT Press; 2008.

16. Eysenbach G. Credibility of health information and digital media: new perspectives and implications for youth. In: Metzger MJ, Flanagin AJ, editors. Digital Media, Youth, and Credibility. The John D and Catherine T MacArthur Foundation Series on Digital Media and Learning. Cambridge, MA: MIT Press; 2008. URL: http://www.mitpressjournals.org/doi/pdf/10.1162/dmal.9780262562324.123 [doi: 10.1162/dmal.9780262562324.123]

17. Eysenbach G. From intermediation to disintermediation and apomediation: new models for consumers to access and assess the credibility of health information in the age of Web2.0. Stud Health Technol Inform 2007;129(Pt 1):162-166. [Medline: 17911699]

18. Eysenbach G, Diepgen TL. Towards quality management of medical information on the internet: evaluation, labelling, and filtering of information. BMJ 1998 Nov 28;317(7171):1496-1500 [FREE Full text] [Medline: 9831581]

19. Eysenbach G. Challenges and changing roles for medical journals in the cyberspace age: electronic pre-prints and e-papers. J Med Internet Res 1999 Dec 31;1(2):E9 [FREE Full text] [Medline: 11720918] [doi: 10.2196/jmir.1.2.e9]

20. Peer review and fraud. Nature 2006 Dec 21;444(7122):971-972. [Medline: 17183274] [doi: 10.1038/444971b]

21. Slotnik DE. Too Few Friends? A Web Site Lets You Buy Some (and They Are Hot). New York Times. 2007 Feb 26. URL: http://www.nytimes.com/2007/02/26/technology/26fake.html?_r=2&oref=slogin&oref=slogin [WebCite Cache ID 5aL53Dtz3]

22. Schleyer T, Spallek H, Butler BS, Subramanian S, Weiss D, Poythress ML, et al. Facebook for scientists: requirements and services for optimizing how scientific collaborations are established. J Med Internet Res 2008;10(3):e24 [FREE Full text] [Medline: 18701421] [doi: 10.2196/jmir.1047]

23. Falkman G, Gustafsson M, Jontell M, Torgersson O. SOMWeb: A Semantic Web-Based System for Supporting Collaboration of Distributed Medical Communities of Practice. J Med Internet Res 2008;10(3):e25 [FREE Full text] [Medline: 18725355] [doi: 10.2196/jmir.1059]

24. Berners-Lee T. IBM developerWorks pod cast, recorded 7-28-2006 (Transscript). IBM. IBM. URL: http://www-128.ibm.com/developerworks/podcast/dwi/cm-int082206.txt [WebCite Cache ID 5aL8Cp6Zf]

Abbreviations

API: application programming interface
PCHR: Personally Controlled Health Record
PHA: Personal Health Application
PHR: Personal Health Record

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Review

Health 2.0 and Medicine 2.0: Tensions and Controversies in the Field

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Abstract

Background: The term *Web 2.0* became popular following the O'Reilly Media Web 2.0 conference in 2004; however, there are difficulties in its application to health and medicine. Principally, the definition published by O'Reilly is criticized for being too amorphous, where other authors claim that Web 2.0 does not really exist. Despite this skepticism, the online community using Web 2.0 tools for health continues to grow, and the term *Medicine 2.0* has entered popular nomenclature.

Objective: This paper aims to establish a clear definition for Medicine 2.0 and delineate literature that is specific to the field. In addition, we propose a framework for categorizing the existing Medicine 2.0 literature and identify key research themes, underdeveloped research areas, as well as the underlying tensions or controversies in Medicine 2.0's diverse interest groups.

Methods: In the first phase, we employ a thematic analysis of online definitions, that is, the most important linked papers, websites, or blogs in the Medicine 2.0 community itself. In a second phase, this definition is then applied across a series of academic papers to review Medicine 2.0's core literature base, delineating it from a wider concept of eHealth.

Results: The terms *Medicine 2.0* and *Health 2.0* were found to be very similar and subsume five major salient themes: (1) the participants involved (doctors, patients, etc); (2) its impact on both traditional and collaborative practices in medicine; (3) its ability to provide personalized health care; (4) its ability to promote ongoing medical education; and (5) its associated method- and tool-related issues, such as potential inaccuracy in enduser-generated content. In comparing definitions of Medicine 2.0 to eHealth, key distinctions are made by the collaborative nature of Medicine 2.0 and its emphasis on personalized health care. However, other elements such as health or medical education remain common for both categories. In addition, this emphasis on personalized health care is not a salient theme within the academic literature. Of 2405 papers originally identified as potentially relevant, we found 56 articles that were exclusively focused on Medicine 2.0 as opposed to wider eHealth discussions. Four major tensions or debates between stakeholders were found in this literature, including (1) the lack of clear Medicine 2.0 definitions, (2) tension due to the loss of control over information as perceived by doctors, (3) the safety issues of inaccurate information, and (4) ownership and privacy issues with the growing body of information created by Medicine 2.0.

Conclusion: This paper is distinguished from previous reviews in that earlier studies mainly introduced specific Medicine 2.0 tools. In addressing the field's definition via empirical online data, it establishes a literature base and delineates key topics for future research into Medicine 2.0, distinct to that of eHealth.

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Introduction

O'Reilly defines Web 2.0 by a series of case examples, noting the characteristics of a Web 2.0 company, such as (1) hard-to-recreate data sources that get richer as more people use them, (2) harnessing collective intelligence, and (3) levering the "long tail" through customer self service [1]. However, critics have claimed this definition is too amorphous [2] and have attempted to narrow it [3]. Despite these attempts, researchers can view Web 2.0 in its widest sense, incorporating all tools such as search (eg, Google) and Podcasts [4,5]. Since many top websites [6] encompass some of these characteristics, such as use of RSS feeds, it poses a concern that Web 2.0 and the Internet are synonymous. Furthermore, existing research fields in medicine, such as interactive health communication applications (IHCAs), overlap significantly with components of Medicine 2.0. These ambiguities imply that Medicine 2.0 is not a separate research field.

However, we argue that Medicine 2.0 has certain characteristics that warrant analysis distinct from eHealth. First, there is the number of online references to Web 2.0, Health 2.0, and Medicine 2.0 (187-224 million, 0.5-1.7 million, and 0.1-0.4 million, respectively, depending on the search engine used). Second, there is extensive literature loosely associated with O'Reilly's definition, such as Wikinomics [7], Democratizing Innovation [8], or the literature identified in this review. Third, related topics such as IHCAs and eHealth either do not cover all aspects of Medicine 2.0 or have a different focus. For instance, IHCAs were defined before recent Internet developments such as Wikipedia, which is reflected in doubts about which sites apply to IHCAs [9]. Hence, we believe the main issue is that a clearer definition or demarcation of Medicine 2.0 is warranted.

We employ data garnered from practising online communities to answer the following research questions:

1. Can a clear definition of Medicine 2.0 be established across practitioner and academic literature that distinguishes this field from eHealth?
2. Is there agreement between online discussions and academic communities in their use of the term *Medicine 2.0*? If not, what does such divergence imply for future research?
3. What are the major tensions between the main stakeholders in Medicine 2.0 communities as identified by research?

Toward this aim, we used Google's PageRank system to identify the most popular online discussions and delineate key themes through thematic analysis. We started by clarifying the Web 2.0 definition as some researchers suggest that aspects of its application to medicine cannot be assumed [10]. We then examined both academic literature and online discussions to find key identifying terms and salient themes associated with Medicine 2.0 (or other health "2.0"–related terms). Indeed, the Medicine 2.0 definition was found to be different from simply applying the rule "Medicine 2.0 = Medicine + Web 2.0," particularly in its emphasis on personalized health care and its participants. In addition, we found only minor differences between the salient themes in Health 2.0 and Medicine 2.0.

In a second phase, we applied these salient themes as a definition to the academic literature associated with Medicine 2.0 to broadly delineate the field. In doing this, we found four major tensions in the field. Moreover, we determined that academic literature does not explore personalized or customized health care in the detail that this theme is treated online. Finally, as could be expected, we found a gray area with papers that clearly have implications for Medicine 2.0 but do not correspond to many of the salient themes associated with it.

This paper makes a distinct contribution to the Medicine 2.0 field by empirically demarcating its thematic boundaries and differentiating it from Web 2.0 and Health 2.0, as well as online versus academic perspectives.

Methods

Identifying Medicine 2.0 Salient Themes and Vocabulary

Medicine 2.0 focuses strongly on the use of Web 2.0 tools. However, as a term only four years old and constantly evolving as new tools emerge, academic literature is unlikely to have achieved consensus on its scope as quickly as 2008. For this reason, we used Google's PageRank system to identify the tools or benefits most important to Web 2.0. Google's PageRank relies on the democratic nature of the Web's vast link structure to indicate an individual page's value. Google interprets a link from page A to B as a vote by page A for page B. Google looks at more than the sheer volume of votes; if the page that casts the vote also has many links to it, this vote cast by that page weighs more heavily [11].

To refine the approach, and to enable a contrast to Medicine 2.0's salient themes, we started with Web 2.0. We searched with Google for "Web 2.0" to identify the most linked pages with the term. These pages were coded using thematic analysis [12] to identify the terms describing both tool types and the purpose or benefits of Web 2.0. Articles coded included not only the Wikipedia entry and O'Reilly's definitions, but also a series of blog threads, including over 50 contributions from users attempting to define Web 2.0. The full results of this approach are available in a separate publication [13], but we adapted the approach for this paper and used the result, which summarizes Web 2.0 as:

Democratized Collaborations; a collaboration enabled by web technology that promotes learning and innovation. Democratized collaborations work by connecting participants to harness network effects and knowledge in an open and interactive manner.

Defining Medicine 2.0

A similar approach was used to delineate Medicine 2.0, but no assumption was made that identifying terms such as *Medicine 2.0* should take precedence over *Physician 2.0* as the researchers had a priori knowledge that numerous terms are associated with the field. Hence, in the first two steps in the method below, we try to determine the identifying terms that describe the field. Step 3 identifies the most popular online discussions relevant to the field, and, finally, steps 4-6 use the comparative method

for thematic analysis as described by Techniques and Procedures for Developing Grounded Theory [12] to understand the salient themes. Steps 3-6 were effectively completed three times in order to obtain intercoder reliability of 82% agreement for exact phrases across all of the pages analyzed.

In a second phase, carried out in step 7, the original sample of 2405 academic papers identified as being potentially related to Web 2.0 and health was reduced to 56 papers after excluding those not directly addressing Medicine 2.0, duplicate search results, or papers not available in English. The initial number of papers and those selected for the review are shown in brackets in step 1 of the methodology outlined in Table 1.

Table 1. Methodolocial steps

Step	Purpose	Description
1	Determine the field's identifying terms from academic literature	We examined journals through search tools including PubMed (170:16), Blackwell Synergy (159:3), Science Direct (52:2), Emerald Insight (21:1), SpringerLink (20:1), JAMA (10:1), Wiley Interscience (109:0), and Google Scholar (1864:32). Any paper with a combination of "web" and "2.0" and restricted to medicine or health science journals was considered. The Google Scholar search was based on "Web 2.0" and "medicine" or "health." All key "2.0" terms found in these paper titles or abstracts were identified (eg, "Medicine 2.0"). This and subsequent use of literature covers papers up to the end of March 2008.
2	Determine the popularity of academic literature's identifying terms online	These terms were used to search Google to determine the support for the particular term (eg, the number of references matching "Health librarian 2.0") online.
3	Determine the most popular pages associated with the identifying terms	Identifying terms with the most online references (eg, "Health 2.0" and "Medicine 2.0") were used as a search term in Google to identify the most popular associated pages. Google's PageRank system returns the most popular and most viewed pages as denoted by the richer-get-richer phenomena noted by a number of authors [14,15]. While these pages are the most popular, their contribution to the field may not be the most important [16], necessitating step 5.
4	Identify salient themes using thematic analysis	The online discussions in the popular pages were analyzed by two researchers using thematic analysis [12] to identify salient themes. This process involves open coding, axial coding, and selective coding in an iterative process of analyzing qualitative data (ie, text). Units of text (ie, words, phrases, sentences, or paragraphs) are labeled, compared, and grouped until no new categories emerge. Coders were instructed to look for manifest-type content that describes the field. Manifest content is that which resides on the surface of communication and is therefore easily observable, as this can improve reliability and puts less interpretative burden on coders [17]. As such, exact phrases that were found in the pages were used, though the unit of analysis combined both the exact phrase and the theme (an approach noted in studies such as [18]).
5	Identify order of importance of pieces of exact phrases associated with salient themes	As noted in step 3, the most popular pages do not necessarily make the only important contributions to define the field, even though they do potentially play a more important role than other pages. The exact phrases associated with the different salient themes identified were re-entered into four different search engines to understand their frequency of use online or their relative ranking. By ranking, we mean the frequency of use as indicated by the count function of the search engine compared to other phrases using the same search engine. The search text included the identifying term as set out in Table 2. In this way, we were able to identify the importance of this exact phrase across all online content, reducing reliance on the popular pages analyzed. Exact phrase within themes were excluded if they did not have minimum counts that met search engine reliability thresholds (eg, less than 1000 for Google, 8000 for Microsoft Live Search) [19,20].
6	Identify further salient themesuntil saturation	Additional online descriptions continued to be coded until saturation (eg, nine online articles were examined for Health 2.0, and the next two examined did not identify any phrases with over a 1000 counts online). At this point, the independent coders compared and returned to step 3, where required, to address interrater reliability and integrity.
7	Define field scope and review academic literature to determine related publications and key tensions	This understanding of salient themes and the frequency of use of exact pieces of text online was used to provide an updated definition of Medicine 2.0 and structure the academic literature into key themes. The original set of academic papers identified in step 1 was critically examined to determine if the papers were, in fact, Medicine 2.0, to clearly delineate between Medicine 2.0 and eHealth literature. Two researchers independently assessed the literature to determine if it was specific to Medicine 2.0. The differences were resolved by discussion between the two researchers. Key tensions were identified via discussions with the whole research team.

Results

Determine Field's Identifying Terms

The abstracts and titles of the 2405 papers indicated that "2.0" was associated with Health 2.0, Medicine 2.0, Physician 2.0, Nursing Education 2.0, Medical Librarian 2.0, and Physician Learning 2.0.

Determine the Popularity of Identifying Terms Online

Table 2 shows how often the terms used by academics are replicated in the community itself (via Google search). The results show that "Health 2.0" or "Health" and "Web 2.0" are the most commonly discussed terms. The prominence of Health 2.0 and Medicine 2.0 meant only these terms were examined for more precise definitions as detailed by steps 3-6 in the Methods.

Table 2. Online use of "2.0" terms identified in academic literature

Search Term	Google Count
"health" and "web 2.0" or "health 2.0"	1,617,000
"medicine" and "web 2.0" or "medicine 2.0"	474,900
"physician 2.0" or "physician" and "web 2.0"	126,000
"medical librarian 2.0" or "medical librarian" and "web 2.0"	9560
"nursing education 2.0" or "nursing education" and "web 2.0"	5612
"physician learning 2.0" or "physician learning" and "web 2.0"	271

Identify Salient Themes and Popularity of Associated Phrases

For both terms, open coding of the top online descriptions quickly lead to saturation, in the case of Medicine 2.0, after seven articles (articles coded: [4,21-25]) and after nine for Health 2.0 (articles coded: [26-34]). In the early axial and selective coding stages, four core terms were identified: participants or actors, tools, methods, and purpose or objectives. The salient themes or grouping applied to both identifying terms, and there was almost no difference with the ranking (in terms of counts) of exact phrases associated with these themes. Overall, there were few differences between Health 2.0 and Medicine 2.0 in terms of participants, and Table 3 and Table 4 show the individual counts for each term. It is worth noting than one exact phrase, "Privacy," was identified by both researchers but was not possible to rank using search engines. Different search engines provided widely different rankings for this term (from first to last within the methods and tools grouping), which we believe reflected the fact that some search engines perform key word searchers through the footers of cached pages (see Discussion).

Table 3. Medicine 2.0: relative frequency of use of associated text

Salient Theme	Associated Exact Phrase	Ranking (relative frequency of use online)				
		Google	Yahoo!	MSN	Ask.com	Average Rank
Participants	Doctors, physicians	1	1	1	1	1
	Patients	2	2	2	2	2
	Scientists	3	3	3	3	3
	Nurses	4	4	4	4	4
	Medical students	5	5	5	5	5
	Medical librarians	6	6	6	6	6
Tools	Podcast	1	1	1	1	1
	Blog	2	2	2	2	2
	Bookmarking, tagging	3	3	5	4	3.75
	Search engine	4	4	6	5	4.75
	Wiki	5	5	3	6	4.75
	RSS feed	6	6	4	3	4.75
Methods	Commons, open access	1	1	1	1	1
	Wisdom of crowds, network effects	2	2	3	4	2.75
	User generated content	3	3	4	3	3.25
	Accuracy	4	4	2	2	3
	Expert community	5	5	5	5	5
Purpose/ Objectives	Collaborate, facilitate collaboration	1	1	1	1	1
	Personalized, customized information	2	2	2	2	2
	Medical education	3	3	3	3	3
	Free access, free services	5	4	4	4	4.25
	Stay informed	6	5	5	5	5.25
	Communication tool	4	6	6	6	5.5
	Create knowledge	7	7	7	7	7

Table 4. Health 2.0: relative frequency of use of associated text

Salient Theme	Associated Exact Phrase	Ranking (relative frequency of use online)				
		Google	Yahoo!	MSN	Ask	Average Rank
Participants	Doctors, physicians	1	1	1	1	1
	Patients, citizens	2	2	2	2	2
	Scientists	3	3	3	3	3
	Medical students	4	5	6	4	4.75
	Nurses	5	4	4	5	4.5
	Clinicians	6	6	5	6	5.75
	Health professionals	7	7	7	7	7
	Caregivers	8	8	8	8	8
	Medical librarians, health librarians	9	9	9	9	9
Tools	Blog	1	1	1	1	1
	Podcast	2	2	2	2	2
	Tagging, bookmarking, social search	3	3	6	3	3.75
	Search engine	4	4	4	4	4
	RSS feed	6	6	3	5	5
	Wiki	5	5	5	6	5.25
	Mashup	7	7	7	7	7
Methods	Open source, open platforms	1	1	1	1	1
	User generated, user innovation	2	2	2	2	2
	Participation, power of networks	3	3	3	3	3
	Aggregation	4	4	4	4	4
	Taxonomy	5	6	6	5	5.5
	Reliable information, medical errors	6	5	5	6	5.5
	Virtual communities, social groups	7	7	7	7	7
Purpose/Objectives	Long tail, personalized	1	1	1	1	1
	Collaboration	2	2	3	2	2.25
	e-learning, medical education, mobile learning, health education, active learning	3	3	2	3	2.75
	Community	4	4	5	4	4.25
	Online services	5	5	4	5	4.75
	Knowledge sharing	6	6	6	6	6
	Information infrastructure	7	7	8	7	7.25
	Reference tool	8	8	7	8	7.75

Define Field Scope and Review Academic Literature

Given the similar definitions of Health 2.0 and Medicine 2.0, and as suggested by other authors to encapsulate research [35,36], we decided to use the term *Medicine 2.0.* However, choosing either term would not have highly impacted the results of the literature review. The ranking of the terms and the context of use in the pages that we analyzed suggested the following definition for Medicine 2.0:

> *Medicine2.0 is the use of a specific set of Web tools (blogs, Podcasts, tagging, search, wikis, etc) by actors in health care including doctors, patients, and scientists, using principles of open source and generation of content by users, and the power of networks in order to personalize health care, collaborate, and promote health education.*

Supporting this are five salient or structuring themes that we more accurately define as follows:

1. Participants: the different stakeholders in Medicine 2.0
2. Method/tools: the manner by which Medicine 2.0 information is created and owned (eg, its accuracy from

user generation, open source or ownership, and the use of specific tools such as wikis)

3. Collaboration and practice: Medicine 2.0 as a tool to promote participant's interests as a reader (staying informed) or to communicate and collaborate collectively for his or her own practice

4. Medical education: Medicine 2.0's educational use for the general public, training new health professionals, or ongoing education for specialists (different than collaboration and practice in its promotion of general skills, as opposed to examining and collaboration on a patient's particular case)

5. Personalized health: Medicine 2.0 as a mechanism to provide customized health care, such as connecting patients with rare conditions, and to improve an individual's value from health care

Discussion

Research Question 1: Definition

Can a clear definition of Medicine 2.0 be established across practitioner and academic literature that distinguishes this field from eHealth? Examining this question, we found common salient themes for both Health 2.0 and Medicine 2.0 that describe Web 2.0's application to health. Its application to health and medicine is not as straightforward as the rule "Medicine 2.0 = Medicine + Web 2.0," particularly in its emphasis on personalized health care and its participants (not observed in the Web 2.0's democratized collaborations [13]). In addition, while we did not complete a systematic review of eHealth, previous publications have shown that the field emphasizes the "communicative foundations of eHealth and specif[ies] the use of networked digital technologies, primarily the Internet...for all stakeholder groups" [37]. As such, neither the stakeholders nor the principal tool used (the Internet) distinguishes Medicine 2.0 from eHealth. However, the principles of open source, generation of content by users, the power of networks, personalized health care, and the focus on collaboration across all stakeholders are not always highlighted by eHealth and suggest that these fields have different emphasis.

In addition, earlier in this paper we highlighted the issue that the technology based view of Medicine 2.0 (ie, the use of Web 2.0–like tools) could not clearly distinguish eHealth from Medicine 2.0. For example, we could conclude that every Internet health search using Google becomes a Medicine 2.0 search as the search algorithm is based on user-generated links. However, our definition implies that this cannot be taken for granted as Google does not meet many criteria of the Medicine 2.0 definition. First, it is not open; users do not have transparency on the algorithm or the ability to change it. Second, users do not have an intention to collaborate using Google or to help Google when assigning a link within a page. Rather, Google has commercialized a feature of Internet collaboration for its search and has not created a Medicine 2.0 collaborative platform. Despite this, other authors have argued that Google is the quintessential Web 2.0 company [38] and its use of network effects and user generated content will mean it will probably remain across the eHealth and Medicine 2.0 gray boundary.

Applying this definition to the original set of articles identified via key word searches on health and Web 2.0, we found that fewer papers were associated with the field. One main driver was the fact that the search terms (eg, "Medicine 2.0") often found identified papers that had no relevance to the subject, though we did not bottom at the root cause of this effect. Others were relevant to eHealth in general, but not Medicine 2.0. For example, the study "Influences, usage, and outcomes of Internet health information searching: multivariate results from the Pew surveys" by Rice [39] provides detailed analysis on the use of the Internet in relation to health, but it does not address Medicine 2.0 issues specifically. A few papers ended on a similar gray boundary to that demonstrated by Google, such as Tse et al [40], and these were excluded from our review. This does not mean their findings are not relevant, but rather we found that the overall paper was not specific to Medicine 2.0 and should consequently be treated as an eHealth paper with potential implications for Medicine 2.0.

Finally, we noted that rapid saturation in coding was achieved to obtain the salient themes used online. And while we believe this reflects a certain amount of common language used by the Health 2.0 or Medicine 2.0 online community, this does not mean all relevant themes were identified. For instance, social networking is only encapsulated in the "power of networks," even though some authors would identify this as a very important separate trend and term. As such, this definition only identifies core or salient themes, not excluding other concepts, as being part of Medicine 2.0. We believe any compact definition will have difficulty in precisely delineating its complete scope.

Research Question 2: Agreement

Is there agreement between online discussions and academic communities in their use of the term *Medicine 2.0*? If not, what does such divergence imply for future research? Regarding research question 2, we identified 56 articles in the research literature that covered four of the five major themes underpinning the Medicine 2.0 definition. In reviewing the literature and comparing it to prominent online themes, we found limited research into personalized health but did find extensive literature on methods and tools. We also noted potential overlaps with a separate body of research into open source health and a general call by authors for further research in specific areas.

Despite the fact that personalized or customized health is a key objective or benefit of Medicine 2.0 (based on online discussions such as those typified by [41]), no academic publications were found that focused extensively on this theme. Specifically, we believe researchers may need to look at how personalized online health care can evolve, such as the trade-offs between an active global site (with rich, regular but fairly uncustomized updates) versus a local site with very specific information to a regional context (but with less contributors and, hence, the risk of inaccuracy or less information).

By contrast, research responding to the tools and methods is the most extensive. In this theme, papers looked at the implications of a particular tool or method, such as the errors in user-generated content or the implications of open-source

methods. For example, Deshpande and Jadad [42] offer an overview of the methods or drivers of Medicine 2.0, providing some support for our identified themes and definition. In addition to information inaccuracy and privacy, open-source methods have been widely studied within this theme relating to medical research. Examples can be categorized into two types: those that address the issues and benefits of a common license for the output of research (eg, [10,43]), and those that look at open-source methods to develop information technology tools for medical research (eg, [44,45]). However, open-source health is not subsumed by Medicine 2.0. The extensive literature on open source, such as the 3864 articles in PubMed as of February 2008, covers topics outside Medicine 2.0. For example, Hope [10] explores technology licensing not connected with Internet use, as opposed to Yang et al [46], who do consider a Medicine 2.0 open-source collaboration. As such, while Medicine 2.0 relies on open-source methods in health, and the topics overlap in areas, we believe care should be taken to view them as distinct research topics.

Overall, there is a call for research in many areas, and Potts [47] suggests that researchers are significantly behind trends in

eHealth and, more specifically, in Medicine 2.0 tools such as the use of blogs and wikis. Potts argues that extensive research is required to close this gap, which is supported by other researchers' calls for more evidence to understand best practice models in using Medicine 2.0 for medical education and practice [48-51].

In addition to this call for research, we would expect publications on Medicine 2.0 to continue to grow in this theme for two further reasons. First, Web 2.0 tools are constantly evolving, and hence the impact of new tools will continue to require assessment. Second, two major tensions or research discussions exist that will also require investigation: information inaccuracy, and information privacy and ownership. We return to these tensions in the discussion on research question 3, and detail them in Table 5 along with how papers responded to salient themes. Note that some papers investigate Medicine 2.0's impact for various stakeholders (indicated by "various" in Table 5), while others either touch on multiple themes or are difficult to classify (indicated by "over-arching or unclassified" in Table 5).

Table 5. Medicine 2.0 literature organized by themes and participants

Salient Theme	Year	Author	Principle Participant	Tensions
Over-arching or unclassified	2006	Skiba [52]	Researchers/scientists	Field's existence
	2007	Manhattan Research [53]	Doctors	n/a
		Ferguson [54]	Patients/public health	Doctor's concerns
				Privacy and ownership
	2008	Eysenbach [35,36]	Various	Field's existence
		Versel [55]	Various	Field's existence
		Guistini [56]	Various	Field's existence
Tools and methods	2002	Burk [43]	Researchers/scientists	n/a
	2003	Killion et al [44]	Researchers/scientists	n/a
	2004	Boyle et al [45]	Researchers/scientists	n/a
	2005	Boulos et al [57]	Various	n/a
		Hope [10]	Researchers/scientists	n/a
	2006	Boulos et al [51]	Various	Information inaccuracy
		Boulos and Honda [58]	Various	n/a
		Castel et al [59]	Various	n/a
		Johnson et al [60]	Various	n/a
		Guistini [61]	Doctors	n/a
		Barsky [62]	Medical librarians	n/a
		Barsky [63]	Medical librarians	n/a
		Barsky and Purdon [64]	Medical librarians	n/a
		Karkalis and Koutsouris [49]	Patients/public health	Privacy and ownership
		Esquivel et al [65]	Patients/public health	Information inaccuracy
	2007	Boulos and Wheeler [47]	Various	n/a
		Liesegang [66]	Various	n/a
		Yang et al [45]	Researchers/scientists	n/a
		Saval et al [67]	Doctors	n/a
		Adams [68]	Patients/public health	n/a
		Boulos and Burden [69]	Patients/public health	Privacy and ownership
		Boulos et al [70]	Patients/public health	n/a
		Van den Brekel [71]	Patients/public health	n/a
		Barsky and Cho [30]	Medical librarians	n/a
		Barsky and Guistini [33]	Medical librarians	n/a
		Cho [72]	Medical librarians	n/a
		Connor [73]	Medical librarians	n/a
	2008	Eysenbach [74]	Patients/public health	Information inaccuracy

Collaboration and practice	2004	Eysenbach et al [75]	Patients/public health	n/a
	2006	Guistini [4]	Doctors	n/a
		Atreja et al [76]	Doctors	n/a
		Navarro et al [77]	Patients/public health	n/a
		Altmann [78]	Various	n/a
	2007	Bonniface et al [79]	Patients/public health	n/a
		Steyn and de Wee [80]	Medical librarians	n/a
		Mclean et al [50]	Doctors	n/a
		Potts [47]	Researchers/scientists	Field's existence
Medical education	2006	Goh [81]	Patients/public health	Doctor's concerns
		Boulos et al [82]	Various	n/a
	2007	Heller et al [83]	Patients/public health	n/a
		Crespo [84]	Patients/public health	n/a
		Skiba [85]	Nurses	n/a
		Skiba [86]	Nurses	n/a
		Skiba [87]	Nurses	n/a
		Skiba [88]	Nurses	n/a
		Sandars and Schroter [5]	Medical students	Doctor's concerns
		Sandars and Haythornthwaite [89]	Medical students	n/a
	2008	McGee [90]	Medical Students	n/a
		Sandars [91]	Medical Students	Privacy and ownership

Research Question 3: Tensions

What are the major tensions between the main stakeholders in Medicine 2.0 communities as identified by research? In relation to research question 3, four key areas of debate or tension between stakeholders were identified by our literature review:

1. The field's existence: The definition of Medicine 2.0 and its existence as a legitimate research field, which this paper addresses, is an overarching issue, but it mostly concerns researchers.
2. Doctors' concerns with patients' use of Medicine 2.0, even if the information is accurate: This tension will mostly play out between doctors and patients in regular practice.
3. Information inaccuracy and potential risks associated with inaccurate Medicine 2.0 information: While this will concern all participants, it will be researchers, doctors, and patients who will have to understand the risks and techniques involved.
4. Privacy and ownership issues with Medicine 2.0–generated information: This may include such things as patient groups driving research agendas in addition to those sought by doctors and scientists.

The first main area of debate, an overarching theme, is related to the lack of agreement on what Web 2.0 is, and if it really exists [2]. Studies have generated justification for the study of Web 2.0 by the sheer size of its participants and the number of people who recognize it as a concept [92]. This debate has trickled into the Medicine 2.0 domain in discussions by people such as Skiba [52] and is continued by speculation that terms

such as *Health 2.0* may be a fake "gold rush" [55]. The situation is complicated further by authors introducing Web 3.0 for medicine, speculating that some Web 2.0 tools such as social bookmarking will become redundant [56]. However, we believe people will continue to use Medicine 2.0 tools, and some researchers have argued that Medicine 2.0 and Health 2.0 may evolve into terms with relevance for different audiences, such as Medicine 2.0 as an academic and international focus, versus a business or consumer audience for Health 2.0 [35,36]. Our results neither confirm nor reject this hypothesis, but they do provide support for the idea that the terms currently have a high degree of overlap and that both are more complex than simply applying Web 2.0 to a health care context.

The second main debate surrounds collaboration and practice by doctors and patients. Separate to the issues of information inaccuracy, it encompasses resistance by some doctors to their patients' use of Medicine 2.0. Their concerns arise from Medicine 2.0 causing unwanted behaviors in patients, such as not consulting a physician, consulting a physician too late, or coming to wrong conclusions about their disease management even if the information available to them online is accurate. The issue is not new and arose with eHealth. Ferguson [54] calls these doctors "e-Patient resistant clinicians" and suggests a sense of loss of control (and risk of being sued), paternalism, or lack of training driving these doctors' behaviors. However, the issue is distinct in Medicine 2.0, where amplifying effects to this behavior are identified by certain authors, such as lack of training for doctors [5] or the difficulty of advising patients on use of Medicine 2.0 tools [81]. Overall, authors claim that

doctors will need to recognize the emergence of Medicine 2.0 and that current training may not be sufficient to do so.

The third main discussion, based on the methods used to generate Medicine 2.0 information, is the risk of inaccurate online information. Misinformation has long been identified as a hazard of eHealth. However, studies have found little support for this concern [93]. These studies pre-date the rapid expansion in Medicine 2.0 use. Looking more closely at Medicine 2.0–specific information, Esquivel [65] notes the error and correction rate on an Internet-based cancer support group. The study found that most information was accurate and most false or misleading statements were rapidly corrected. Eysenbach [74] also examined the impact of information accuracy and credibility in relation to eHealth and noted that that patients will tend to use both intermediated (experts, authorities) and distributed (ie, Medicine 2.0) information to make their health decisions, thereby reducing any risk from inaccurate online information generated by users. In addition, apomediaries or gatekeepers acting at the network or group level work as collaborative filtering processes for distributed information that help users navigate through the onslaught of information afforded by networked digital media, reducing information risk further [35,36]. However, despite this early evidence of low risk, many practitioners and researchers remain to be convinced. This is demonstrated by responses to articles on Medicine 2.0's potential, such as "the consequences could be disastrous for any inexperienced trainee following the advice" [4], or the need for authors to post a clarification after suggesting that Google could be used as a diagnostic tool [38].

The fourth and final debate is related to the consequences of the methods used to generate Medicine 2.0 information. Authors note that in addition to accuracy of information, privacy, ethical, legal, and ownership issues are also critical due to the nature of health information [49,69]. This applies not only to patients but to doctors who may use social networking sites for medical education and debate [91]. They suggest that potential models of identity management and authorization schemes should also be investigated in the context of Medicine 2.0 research. Once again, this tends to accentuate eHealth trends such as noted by Ferguson [54], who also highlights that those patient groups who run specific sites claim ownership over this data and are increasingly using it to influence the research agenda. Overall, new sources of health information are emerging via these methods, which will impact not only doctors who carry out research but could have potential implications for scientists working in the wider industry, such as pharmaceutical companies.

Potential Limitations

Our study has several limitations that warrant attention. Clear risks arise from using Google and other search engines to define Medicine 2.0. First, in step 3 of the method, Google's PageRank system may only identify popular self-referencing communities, which as noted by some researchers has bias against newer online content [16]. Second, search algorithms are rarely published, and hence we cannot be sure of the consistency of the counts, which has been subject to criticism at low levels for both Google and MSN searches [19,20].

We mitigated the first risk via the iterative manner in which the definitions and themes were identified by comparing academic and online definitions for inconsistencies and by searching for theme rankings across all pages online to reduce the bias toward the popular pages. We did not find any major inconsistencies, even though the small differences in Medicine 2.0's scope online and in academic publications were established. Examples include the online focus on personalized health and the lack of online focus on social networking, which has been identified as an important trend by other authors [35,36]. Other exact phrases that we anticipated but did not see included "semantic Web." To mitigate their potential omission, we determined their ranking anyway, but due to lower rankings, they would not have emerged in the defining text of top salient themes used in our paper. This does not indicate that these are not very important themes, but rather that they are covered in more general concepts such as the power of networks.

We also examined the specific criticisms, such as Google returning inconsistent results below 1000 counts or Microsoft Live Search being inconsistent below 8000 counts and hence only ranked exact phrases above these levels. However, the use of different search engines further emphasizes that only the top exact phrases (eg, Blog or Podcast rather than Mashup) can be used with confidence to identify the salient themes as there was good agreement between search engines. Hence, we mitigated this risk by only using the top two to three and commonly ranked phrases, avoiding the bias that a term has been ranked highly only due to a particular search engine's internal mechanisms.

Concluding Remarks

Following the updated definition of Medicine 2.0, the literature describes five major themes: (1) the participants involved; (2) the impact on different collaborations and practice; (3) the ability to provide personalized health care; (4) the use in medical education; (5) its associated methods and tools.

There is now an emerging body of research into Medicine 2.0; in addition to the 56 papers we identified that address it directly, there are also many eHealth papers that have indirect implications for Medicine 2.0. Overall, they suggest that Medicine 2.0 will have a large impact on all areas of medical practice. Most of these publications are recent, since 2004, and call for more empirical research on various topics.

We expect research to continue to focus on the four major tensions between stakeholders that were found in the literature: the scope of the field including its definition and existence, the patient-doctor relationships impacted by Medicine 2.0, the methods and tools relating to information accuracy, and the methods and tools related to ownership and privacy. These issues are also found in eHealth; however, Medicine 2.0 is accentuating their impact. While touched on by some overarching publications, the lack of research into personalized health does not indicate that its importance is overstated by online discussions. Rather, we concur with other researchers who suggest that research currently lags behind practice in understanding the implications of Medicine 2.0.

Conflicts of Interest

None declared.

References

1. O'Reilly T. What is Web 2.0. Design patterns and business models. O'Reilly Media. 2005. URL: http://www.oreillynet.com/pub/a/oreilly/tim/news/2005/09/30/what-is-web-20.html [accessed 2008 Feb 08] [WebCite Cache ID 5VSDJTyrx]

2. McFredries P. Technically Speaking The Web, Take Two. IEEE Spectrum 2006;43(6). [doi: 10.1109/MSPEC.2006.1638049]

3. O'Reilly T. Web 2.0 compact definition: trying again. radar.oreilly.com. 2006. URL: http://radar.oreilly.com/archives/2006/12/web-20-compact-definition-tryi.html [accessed 2008 Feb 22] [WebCite Cache ID 5VnksIrwW]

4. Giustini D. How Web 2.0 is changing medicine. BMJ 2006 Dec 23;333(7582):1283-1284 [FREE Full text] [Medline: 17185707] [doi: 10.1136/bmj.39062.555405.80]

5. Sandars J, Schroter S. Web 2.0 technologies for undergraduate and postgraduate medical education: an online survey. Postgrad Med J 2007 Dec;83(986):759-762. [Medline: 18057175] [doi: 10.1136/pgmj.2007.063123]

6. Meattle J. Top 50 websites. Compete. 2007. URL: http://blog.compete.com/2007/10/30/top-50-websites-domains-digg-youtube-flickr-facebook/ [accessed 2008 Feb 07] [WebCite Cache ID 5VR3UGOvv]

7. Tapscott D, Williams A. Wikinomics. New York: Penguin Group; 2006.

8. von Hippel E. Democratizing Innovation. Cambridge, MA: MIT Press; 2005.

9. Kerr C, Murray E, Stevenson F, Gore C, Nazareth I. Internet interventions for long-term conditions: patient and caregiver quality criteria. J Med Internet Res 2006 Jul;8(3):e13 [FREE Full text] [Medline: 16954123] [doi: 10.2196/jmir.8.3.e13]

10. Hope J. Open Source Biotechnology [dissertation]. Canberra, Australia: The Australian National University; 2005.

11. PageRank (Google). Wikipedia. 2008. URL: http://en.wikipedia.org/wiki/PageRank [accessed 2008 Feb 11] [WebCite Cache ID 5VXR1niNY]

12. Strauss A, Corbin JM. Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory. Thousand Oaks, CA: Sage Publications; 1998.

13. Hughes B, Wareham J. Democratized collaborations in big pharma. Paper to be presented at: 2008 Academy of Management Conference, Management of Technology and Innovation [advance publication]. URL: http://program.aomonline.org/2008/Session_Details.asp?print=true&SubmissionID=13754 [accessed 2008 May 12]

14. Cho J, Roy S. Impact of search engines on page popularity. Proceedings of the 13th international conference on World Wide Web. New York: ACM; 2004:20-29. [doi: 10.1145/988672.988676]

15. Cho J, Roy S, Adams RE. Page quality: in search of an unbiased web ranking. Proceedings of the 2005 ACM SIGMOD international conference on management of data. New York: ACM; 2005:551-562. [doi: 10.1145/1066157.1066220]

16. Vaughan L, Thelwall M. Search engine coverage bias: evidence and possible causes. Inf Process Manage 2004;40(4):693-707. [doi: 10.1016/S0306-4573(03)00063-3]

17. Hagelin EM. Coding data from child health records: the relationship between interrater agreement and interpretive burden. J Pediatr Nurs 1999 Oct;14(5):313-321. [Medline: 10554444] [doi: 10.1016/S0882-5963(99)80031-1]

18. Berg BL. Qualitative Research Methods for the Social Sciences. Boston, MA: Allyn and Bacon; 2001.

19. Notess G. Google inconsistencies. Search engine showdown. 2008. URL: http://www.searchengineshowdown.com/features/google/inconsistent.shtml [accessed 2008 Feb 22] [WebCite Cache ID 5VniujWTV]

20. Thelwall M. Extracting accurate and complete results from search engines: case study Windows Live. J Am Soc Inf Sci Technol 2008;59(1):38. [doi: 10.1002/asi.20704]

21. Meskó B. Medicine 2.0. Science roll blog. 2008. URL: http://scienceroll.com/medicine-20/ [accessed 2008 Feb 07] [WebCite Cache ID 5VR0zkpPO]

22. Medicine 2.0 #10 - medicine and the second generation of Internet. Highlight Health 2.0. 2008. URL: http://blog.highlighthealth.info/medicine-20/medicine-20-10-medicine-and-the-second-generation-of-internet-based-services/ [accessed 2008 Feb 07] [WebCite Cache ID 5VR0e4Xyk]

23. Web 2.0 in Medicine. Clinical cases and images. 2008. URL: http://casesblog.blogspot.com/2005/10/web-20-in-medicine.html [accessed 2008 Feb 11] [WebCite Cache ID 5VX5FLJ2S]

24. Castilla V. Medicine 2.0 blog carnival. Web 2.0 and Medicine Blog. 2008. URL: http://web2097.blogspot.com/2007/11/medicine-20-blog-carnival.html [accessed 2008 Feb 11] [WebCite Cache ID 5VX5dw5XY]

25. Castilla V. Medicine 2.0: copyright or creative commons? 2008. Web 2.0 and Medicine Blog. 2008. URL: http://web2097.blogspot.com/ [accessed 2008 Feb 11] [WebCite Cache ID 5VXO2Ukwi]

26. Web 2.0 could be used in health e-learning. eHealth Insider. 2008. URL: http://www.e-health-insider.com/news/item.cfm?ID=2101 [accessed 2008 Feb 11] [WebCite Cache ID 5VX6SDAbK]

27. Sharp J. Web 2.0: beyond open source in health care. Clinical cases and images blog. 2008. URL: http://casesblog.blogspot.com/2007/06/presentation-on-web-20-in-health-care.html [accessed 2008 Feb 11] [WebCite Cache ID 5VX8mW2bO]

XSL•FO
RenderX

28.   Web 2.0 and health care services. Headshift. 2008. URL: http://www.headshift.com/archives/003192.cfm [accessed 2008 Feb 11] [WebCite Cache ID 5VX9hU9ws]

29.   Health Care and Web 2.0. Dental Information and Library Innovations. 2008. URL: http://mblog.lib.umich.edu/dentlib/archives/2006/12/health_care_and.html [accessed 2008 Feb 11] [WebCite Cache ID 5VX9ptxCc]

30.   MacManus R. A Health 2.0 overview, through the eyes of a new diabetic. Read Write Web. 2008. URL: http://www.readwriteweb.com/archives/health_20_overview_diabetes_web.php [accessed 2008 Feb 11] [WebCite Cache ID 5VXJWVrtx]

31.   Web 2.0 - Do people in health get it? Tech 'N' Health. 2008. URL: http://technhealth.blogspot.com/2007/07/web-2.html [accessed 2008 Feb 11] [WebCite Cache ID 5VXJooTIJ]

32.   Barsky E, Cho A. Introducing Web 2.0: social search for health librarians. J Can Health Libr Assoc 2007;28(2):58-61.

33.   Barsky E, Giustini D. Introducing Web 2.0: wikis for health librarians. J Can Health Libr Assoc 2007;28(4):147-150.

34.   Gruber F. I need a medic! A Health 2.0 round-up. Somewhat Frank. 2008. URL: http://www.somewhatfrank.com/2007/11/i-need-a-medic.html [accessed 2008 Feb 11] [WebCite Cache ID 5VXMA53iO]

35.   Eysenbach G. Medicine 2.0 Congress website launched (and Definition of Medicine 2.0 / Health 2.0). Gunther Eysenbach's Random Research Rants. 2008. URL: http://gunther-eysenbach.blogspot.com/2008/03/medicine-20-congress-website-launched.html [accessed 2008 Mar 07] [WebCite Cache ID 5W9GcYyWN]

36.   Eysenbach G. Medicine 2.0: social networking, collaboration, participation, apomediation, and openness. J Med Internet Res 2008;10(3):e22 (forthcoming). [doi: 10.2196/jmir.1030]

37.   Pagliari C, Sloan D, Gregor P, Sullivan F, Detmer D, Kahan JP, et al. What is eHealth (4): a scoping exercise to map the field. J Med Internet Res 2005 Mar 31;7(1):e9 [FREE Full text] [Medline: 15829481] [doi: 10.2196/jmir.7.1.e9]

38.   Tang H, Ng JHK. Googling for a diagnosis--use of Google as a diagnostic aid: internet based study. BMJ 2006 Dec 2;333(7579):1143-1145 [FREE Full text] [Medline: 17098763] [doi: 10.1136/bmj.39003.640567.AE]

39.   Rice RE. Influences, usage, and outcomes of Internet health information searching: multivariate results from the Pew surveys. Int J Med Inform 2006 Jan;75(1):8-28. [Medline: 16125453] [doi: 10.1016/j.ijmedinf.2005.07.032]

40.   Tse MMY, Lo LWL, Chan MF. The use of health technology and information: e-learning technological approach. Cyberpsychol Behav 2007 Dec;10(6):821-826. [Medline: 18085971] [doi: 10.1089/cpb.2007.9947]

41.   Hamilton D. Perspective: personalizing medicine in the age of Health 2.0. Venturebeat.com. URL: http://venturebeat.com/2007/09/20/perspective-personalizing-medicine-in-the-age-of-health-20/ [accessed 2008 May 08] [WebCite Cache ID 5XfkyeXD1]

42.   Deshpande A, Jadad A. Web 2.0: could it help move the health system into the 21st century? J Men's Health Gender 2006;3(4):332-336. [doi: 10.1016/j.jmhg.2006.09.004]

43.   Burk D. Open source genomics. J Sci Technol Law 2002;8:254.

44.   Killion PJ, Sherlock G, Iyer VR. The Longhorn Array Database (LAD): an open-source, MIAME compliant implementation of the Stanford Microarray Database (SMD). BMC Bioinformatics 2003 Aug 20;4(4):32 [FREE Full text] [Medline: 12930545] [doi: 10.1186/1471-2105-4-32]

45.   Boyle EI, Weng S, Gollub J, Jin H, Botstein D, Cherry JM, et al. GO::TermFinder--open source software for accessing Gene Ontology information and finding significantly enriched Gene Ontology terms associated with a list of genes. Bioinformatics 2004 Dec 12;20(18):3710-3715 [FREE Full text] [Medline: 15297299] [doi: 10.1093/bioinformatics/bth456]

46.   Yang IS, Ryu C, Cho KJ, Kim JK, Ong SH, Mitchell WP, et al. IDBD: infectious disease biomarker database. Nucleic Acids Res 2008 Jan;36(Database issue):D455-D460 [FREE Full text] [Medline: 17982173] [doi: 10.1093/nar/gkm925]

47.   Potts HWW. Is e-health progressing faster than e-health researchers? J Med Internet Res 2006;8(3):e24 [FREE Full text] [Medline: 17032640] [doi: 10.2196/jmir.8.3.e24]

48.   Kamel Boulos MN, Wheeler S. The emerging Web 2.0 social software: an enabling suite of sociable technologies in health and health care education. Health Info Libr J 2007 Mar;24(1):2-23. [Medline: 17331140] [doi: 10.1111/j.1471-1842.2007.00701.x]

49.   Karkalis GI, Koutsouris DD. E-health and the Web 2.0. Paper presented at: The International Special Topic Conference on Information Technology in Biomedicine; October 26-28, 2006; Greece 2006.

50.   McLean R, Richards BH, Wardman JI. The effect of Web 2.0 on the future of medical practice and education: Darwikinian evolution or folksonomic revolution? Med J Aust 2007 Aug 6;187(3):174-177 [FREE Full text] [Medline: 17680746]

51.   Boulos MNK, Maramba I, Wheeler S. Wikis, blogs and podcasts: a new generation of Web-based tools for virtual collaborative clinical practice and education. BMC Med Educ 2006 Aug 15;6(1):41 [FREE Full text] [Medline: 16911779] [doi: 10.1186/1472-6920-6-41]

52.   Skiba DJ. Web 2.0: next great thing or just marketing hype? Nurs Educ Perspect 2006 Jul;27(4):212-214. [Medline: 16921807]

53.   White paper: physicians and Web 2.0: 5 things you should know about the evolving online landscape for physicians. 2007. Manhattan Research, LLC. 2007. URL: http://www.manhattanresearch.com/files/PRESS/Physicians_and_Web_2.0_from_Manhattan_Research.pdf [accessed 2008 Jan 22] [WebCite Cache ID 5ZpXzYQFN]

54.   Ferguson T. ePatients white paper. www.e-patients.net. URL: http://www.e-patients.net/e-Patients_White_Paper.pdf [accessed 2008 Jan 22] [WebCite Cache ID 5ZpY7Q7zl]

55.   Versel N. Health 2.0. Will its promise be realized? Manag Care 2008 Mar;17(3):49-52. [Medline: 104617834]

56. Giustini D. Web 3.0 and medicine. BMJ 2007 Dec 22;335(7633):1273-1274. [Medline: 18156223] [doi: 10.1136/bmj.39428.494236.BE]

57. Boulos MNK. Web GIS in practice III: creating a simple interactive map of England's Strategic Health Authorities using Google Maps API, Google Earth KML, and MSN Virtual Earth Map Control. Int J Health Geogr 2005 Sep 21;4:22 [FREE Full text] [Medline: 16176577] [doi: 10.1186/1476-072X-4-22]

58. Boulos MNK, Honda K. Web GIS in practice IV: publishing your health maps and connecting to remote WMS sources using the Open Source UMN MapServer and DM Solutions MapLab. Int J Health Geogr 2006 Jan 18;5(1):6 [FREE Full text] [Medline: 16420699] [doi: 10.1186/1476-072X-5-6]

59. Castel JM, Figueras A, Vigo JM. The internet as a tool in clinical pharmacology. Br J Clin Pharmacol 2006 Jun;61(6):787-790 [FREE Full text] [Medline: 16722847] [doi: 10.1111/j.1365-2125.2006.02682.x]

60. Johnson KR, Freeman SR, Dellavalle RP. Wikis: the application of Web 2.0. Arch Dermatol 2007 Aug;143(8):1065-1066. [Medline: 17709668] [doi: 10.1001/archderm.143.8.1065]

61. Giustini D. Top five (5) podcasting articles in medicine. UBC Academic Search - Google Scholar blog. URL: http://weblogs.elearning.ubc.ca/googlescholar/archives/023989.html [accessed 2008 Jul 22] [WebCite Cache ID 5ZVkUeVMz]

62. Barsky E. Introducing web 2.0: weblogs and podcasting for health librarians. JCHLA/JSBSC 2006;27:33-34.

63. Barsky E. Introducing Web 2.0: RSS trends for health librarians. J Can Health Lib Assoc 2006;27:7-8.

64. Barsky E, Purdon M. Introducing Web 2.0: social networking and social bookmarking for health librarians. J Can Health Libr Assoc 2006;27:65-67.

65. Esquivel A, Meric-Bernstam F, Bernstam EV. Accuracy and self correction of information received from an internet breast cancer list: content analysis. BMJ 2006 Apr 22;332(7547):939-942 [FREE Full text] [Medline: 16513686] [doi: 10.1136/bmj.38753.524201.7C]

66. Liesegang TJ. Web 2.0, library 2.0, physician learning 2.0. Ophthalmology 2007 Oct;114(10):1801-1803. [Medline: 17908589] [doi: 10.1016/j.ophtha.2007.07.038]

67. Savel RH, Goldstein EB, Perencevich EN, Angood PB. The iCritical care podcast: a novel medium for critical care communication and education. J Am Med Inform Assoc 2007 Jan;14(1):94-99 [FREE Full text] [Medline: 17068348] [doi: 10.1197/jamia.M2205]

68. Adams SA. Using blogging tools to help individuals record their experiences: an exploration and review of two commercial web applications in the Netherlands. Stud Health Technol Inform 2007;130:193-203. [Medline: 17917193]

69. Boulos MNK, Burden D. Web GIS in practice V: 3-D interactive and real-time mapping in Second Life. Int J Health Geogr 2007 Nov 27;6:51 [FREE Full text] [Medline: 18042275] [doi: 10.1186/1476-072X-6-51]

70. Boulos MNK, Hetherington L, Wheeler S. Second Life: an overview of the potential of 3-D virtual worlds in medical and health education. Health Info Libr J 2007 Dec;24(4):233-245. [Medline: 18005298] [doi: 10.1111/j.1471-1842.2007.00733.x]

71. van den Brekel AJP. Get your consumer health information from an avatar!: health and medical related activities in a virtual environment. Paper presented at: European Association for Health Information & Libraries Workshop 2007; September 12-15, Krakow, Poland 2007 [FREE Full text]

72. Cho A. An introduction to mashups for health librarians. J Can Health Libr Assoc 2007;28(1):19-22.

73. Connor E. Medical librarian 2.0. Med Ref Serv Q 2007 Dec;26(1). [Medline: 7210545]

74. Eysenbach G. Credibility of health information and digital media: new perspectives and implications for youth. In: Metzger MJ, Flanagin AJ, editors. Digital Media, Youth, and Credibility. The John D and Catherine T MacArthur Foundation Series on Digital Media and Learning. Cambridge, MA: MIT Press; 2008. URL: http://www.mitpressjournals.org/doi/pdf/10.1162/dmal.9780262562324.123 [doi: 10.1162/dmal.9780262562324.123]

75. Eysenbach G, Powell J, Englesakis M, Rizo C, Stern A. Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. BMJ 2004 May 15;328(7449):1166 [FREE Full text] [Medline: 15142921] [doi: 10.1136/bmj.328.7449.1166]

76. Atreja A, Messinger-Rapport B, Jain A, Mehta N. Using Web 2.0 technologies to develop a resource for evidence based medicine. AMIA Annu Symp Proc 2006:847 [FREE Full text] [Medline: 17238467]

77. Navarro A, Voetsch K, Liburd L, Bezold C, Rhea M. Recommendations for future efforts in community health promotion: report of the National Expert Panel on Community Health Promotion. Atlanta, GA: Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Division of Adult and Community Health; 2006.

78. Altmann U. Representation of Medical Informatics in the Wikipedia and its Perspectives. Stud Health Technol Inform 2005;116:755-760. [Medline: 16160349]

79. Bonniface L, Green L. Finding a new kind of knowledge on the HeartNET website. Health Info Libr J 2007 Dec;24 Suppl 1:67-76. [Medline: 18005296] [doi: 10.1111/j.1471-1842.2007.00742.x]

80. Steyn C, de Wee JA. The naked librarian: health librarians in the modern era. Libr Rev 2007;56(9).

81. Goh SH. The internet as a health education tool: sieving the wheat from the chaff. Singapore Med J 2006 Jan;47(1):3-5 [FREE Full text] [Medline: 16397712]

82. Kamel Boulos MN, Harvey FE, Roudsari AV, Bellazzi R, Hernando ME, Deutsch T, et al. A proposed semantic framework for diabetes education content management, customisation and delivery within the M2DM project. Comput Methods Programs Biomed 2006 Sep;83(3):188-197. [Medline: 16934361] [doi: 10.1016/j.cmpb.2006.07.003]

83. Heller R. Capacity building for public health using the Internet. Bulletin of the World Health Organization 2007. [doi: 10.2471/BLT.07.044388]

84. Crespo R. Virtual community health promotion. Prev Chronic Dis 2007 Jun 15;4(3):A75 [FREE Full text] [Medline: 17572979]

85. Skiba DJ. Nursing education 2.0: are Mashups useful for nursing education? Nurs Educ Perspect 2007 Sep;28(5):286-288. [Medline: 17944264]

86. Skiba DJ. Nursing education 2.0: Poke me. Where's your face in space? Nurs Educ Perspect 2007 Jul;28(4):214-216. [Medline: 17715807]

87. Skiba DJ. Nursing education 2.0: second life. Nurs Educ Perspect 2007 May;28(3):156-157. [Medline: 17557638]

88. Skiba DJ. Nursing education 2.0: YouTube. Nurs Educ Perspect 2007 Mar;28(2):100-102. [Medline: 17486800]

89. Sandars J, Haythornthwaite C. New horizons for e-learning in medical education: ecological and Web 2.0 perspectives. Med Teach 2007 May;29(4):307-310. [Medline: 17786742] [doi: 10.1080/01421590601176406]

90. McGee JB, Begg M. What medical educators need to know about "Web 2.0". Med Teach 2008 Mar;30(2):164-169. [Medline: 18464141] [doi: 10.1080/01421590701881673]

91. Sandars J, Homer M, Pell G, Croker T. Web 2.0 and social software: the medical student way of e-learning. Med Teach 2008 Feb 14:1-5. [Medline: 18608950] [doi: 10.1080/01421590701798729]

92. Skiba B, Tamas A, Robinson K. Web 2.0: hype or reality...and how will it play out? A strategic analysis. Arma Partners. 2006. URL: http://www.armapartners.com/files/admin/uploads/W17_F_1873_8699.pdf [accessed 2008 May 1] [WebCite Cache ID 5ZpZL9nb9]

93. Crocco AG, Villasis-Keever M, Jadad AR. Analysis of cases of harm associated with use of health information on the internet. JAMA 2002 Jun 5;287(21):2869-2871 [FREE Full text] [Medline: 12038937]

Versatile, Immersive, Creative and Dynamic Virtual 3-D Healthcare Learning Environments: A Review of the Literature

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Abstract

The author provides a critical overview of three-dimensional (3-D) virtual worlds and "serious gaming" that are currently being developed and used in healthcare professional education and medicine. The relevance of this e-learning innovation for teaching students and professionals is debatable and variables influencing adoption, such as increased knowledge, self-directed learning, and peer collaboration, by academics, healthcare professionals, and business executives are examined while looking at various Web 2.0/3.0 applications. There is a need for more empirical research in order to unearth the pedagogical outcomes and advantages associated with this e-learning technology. A brief description of Roger's Diffusion of Innovations Theory and Siemens' Connectivism Theory for today's learners is presented as potential underlying pedagogical tenets to support the use of virtual 3-D learning environments in higher education and healthcare.

Introduction

Despite the accelerating momentum of the development, application, and adoption of immersive three-dimensional (3-D) virtual worlds by academics as learning innovations [1,8,12,15,27,28,33,34,35], there are some fundamental questions which remain unanswered. Without doubt, one of the most widely discussed of these is the relevance associated with teaching medical/healthcare professionals [2,3,4]. Similar to most basic issues in education, this question leads to challenges at various levels of thought, and it is beneficial to address while the race to adopt and implement highly engaging Web 3-D virtual worlds is watched in healthcare professional education. At the philosophical and cognitive levels, the value associated with learning presents variables that influence the rate of adoption by academics. The purported beneficial qualities of virtual worlds, such as immersion, role-playing opportunities, simulation, and personal interaction associated with the technology and its influence on formative and summative learning outcomes, requires analysis. Therefore, Roger's

Diffusion of Innovations Theory [5] and Siemens' Connectivism Theory [6] for today's learners will serve as theoretical frameworks for this paper. The purpose of this review is to convey knowledge and ideas that have been established concerning the use of 3-D virtual worlds in medical and health professional education to date whilst describing, summarizing, evaluating, and clarifying the current literature.

Virtual Worlds: Overview

A 3-D virtual world, also known as a Massively Multiplayer Virtual World (MMVW), is an example of a Web 2.0/Web 3-D dynamic computer-based application. According to Jutecht [7], the vague term "Web 2.0" is used for what people see as a second form of the World Wide Web (WWW) architecture and applications that enable social publishing, such as blogs and wikis. A few examples of this interactive Web are podcasts, YouTube, and social networks, such as Facebook, Twitter, and TeeBeeDee. Murray [8] outlines many examples of Web 2.0 applications on the Web. Eysenbach [9], found in Barreto [10], explains:

Web 2.0 is a term which refers to a) improved communication and collaboration between people via social-networking technologies, b) improved communication between separate software applications ("mashups") via open Web standards for describing and accessing data, and c) improved Web interfaces that mimic the real-time responsiveness of desktop applications within a browser window.

Currently, the most popular virtual world used by the general public is Linden Lab's Second Life (SL) [11]. It portrays the general qualities of a MMVW which include, but are not limited to, streaming audio/video/TV/YouTube collections, 3-D virtual libraries, virtual tourist attractions and destinations, social interactive venues used by multiple, customized animated characters, a health information island, global preparedness discussions, lectures, conferences, and support groups [12]. Presently, it has 6.5 million virtual residents [13] from over 100 countries. US agencies, such as the Centers for Disease Control and the National Institutes of Health conduct meetings in SL to discuss the educational potential of SL [14]. Kusumoto, Shorrock, Heinrichs, Dev, and Youngblood [15] describe a 3-D

virtual world online simulation incorporating a Massively Multiplayer Online Game (MMOG) platform, which trains healthcare professionals for a mass casualty event. This is an example of how a virtual world may offer information about disaster preparedness. Furthermore, virtual medical universities exist all over the world [16]. Therefore, 3-D virtual worlds may include MMOGs, which is one type of a "serious game" including educational goals; however, the authors of the Horizon Report [17] argue virtual worlds are not games and provide, rather, examples of "pure" virtual worlds, which include SL [11], "There" [18], and "Active Worlds"[19]. Many of the programs allow the user to create 3-D virtual worlds, socialize, shop, and participate in an educational universe, whereas MMOGs are considered to be more "goal oriented" and may include a multitude of players engaged in "collaborative" gaming events of a competitive nature within a 3-D environment [13,17].

Within the virtual 3-D platforms, end users choose a fictitious name from an online menu (eg, the pseudonym of the author is Maggie Waechter) and have the opportunity to create a unique self (eg, human figure, animal or object) known as an "avatar" (Figure 1).

Figure 1. A screenshot of an avatar in Ann Myers Medical Center [20]

The term "avatar" is an old Sanskrit word portraying a deity which takes on a human shape [21]. These are animated figures the user may navigate to stand, sit, fly, dance, gesture, eat, make love, wind surf, swim, move, walk through doors, open drawers, speak, and "teleport" to various regions and areas within the virtual world via a computer's keyboard. Furthermore, the player

may make and design physical objects and use cash (1000 Lindens = US $4.85) in order to purchase such things as planes, boats, hair, birds, and even body parts. The colourful and creative day-night environment that has a built-in weather system incorporates other Web 2.0 social-networking capacities, such as instant messaging (IM), wikis, users' ratings, profiles,

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podcasts, and sharing user-created objects that may be viewed in a virtual world. According to Boulos [12], the current SL program is voice-enabled and provides the player the opportunity to hear other avatar voices based on the avatar's physical location. For example, if an avatar moves away from another avatar, the avatar's voice will become fainter and, vice versa, louder as you navigate closer. The New Medium Consortium (NMC) offers a symposium on the evolution of communication and how to use it in SL. The NMC offers media presentations about the creation of movement and emotion in SL educational virtual worlds [22].

Another idea is embedding Wii [23], a gaming software program created by Nintendo, into SL. This combination may offer a plethora of opportunities for all age groups because gaming may motivate end users to log in and have fun while learning. Wii offers a "motion sensitive controller (Wiimote)" and is therefore very suitable for the geriatric population requiring increased range of motion for the hands while building endurance, strength, and coordination [24]. The Wiimote requires body movements very similar to those demonstrated in traditional physical therapy. The patients do rigorous exercises while playing a game [24]. Also, the Wii medical game, "Trauma Center: Second Opinion," affords players of the game the opportunity to be a surgeon by using the Wiimote. The intuitive nature of the Wiimote allows for experiential learning and the gaming factor may evoke competitiveness, fun, and active learning.

Despite the theme-park atmosphere or paper-doll quality of virtual worlds such as SL, audiences socialize, communicate, build, seek facts, conduct business and participate in other Web 2.0 applications online. Residents in SL may benefit from each other's participation via networks, which offer dynamic, evolving systems reflecting aspects of the semantic web [25,26]. Researchers make it a point to identify and evaluate budding technologies having an effect on teaching and learning in higher education and forecast a timeframe for potential adoption in education [17]. Virtual worlds are currently being used as educational spaces [1] and continue to grow in popularity on campuses and businesses worldwide. Furthermore, access to versions of virtual worlds on the Web, such as "Croquet,"

"Uni-Verse," and "Multiverse" are predicted within two to three years to be mainstream in education [17].

Pedagogical Potential

Many authors are expounding the educational and research potential of virtual worlds and MMOGs [12,13,15,16,25,27,28]; however, educational research involving the use and effectiveness of these innovative technologies is in its infancy. More research is necessary regarding the educational outcomes before collaborative encounters in virtual worlds are adopted [28]. Nonetheless, there are reported advantages to having students engage in these emerging technologies [1]. Learners actively interact with content and role play skills associated with their profession. By allowing students time to interact with other avatars (eg, patients, staff members, and other healthcare professionals) in a safe, simulated environment, a decrease in student anxiety, an increase in competency in learning a new skill, and encouragement to cooperate and collaborate, as well as resolve conflicts, is possible. Active learning takes place due to other participants being in the same virtual world and constructing objects to represent ideas that may enhance self-reflection and knowledge [1]. If a gaming component is associated with the 3-D virtual world, the student may be motivated to log in. High quality 3-D entertainment that is freely accessible via Web browsing facilitates engagement opportunities with individuals or groups of people in an authentic manner that illustrates collective intelligence [29].

Healthcare Professional Education Examples

Another example of a virtual world and MMOG exemplifying global collaboration and fearless creativity is the Advanced Learning and Immersive Virtual Environment (ALIVE) at the University of Southern Queensland (USQ) [30]. The underlying goal of the ALIVE team is to provide educators the opportunity to develop learning content, which is brought to life in 3-D virtual worlds. The ALIVE team provides YouTube video clips on how to use ALIVE Classmate, an online virtual classroom (Figure 2).

Figure 2. ALIVE classmate tutorial via YouTube video [31]

The ALIVE DX Editor [32] is a simple-to-use 3-D multi- or single-user interactive and serious game creator. Individuals may "drag and drop" 3-D scenes from a gallery and create 3-D learning environments for distribution via the Web or on a Compact Disc Read-Only Memory (CD-ROM).The Carrick Foundation funds the ALIVE project and USQ's Vice Chancellor's Strategic Development Fund and continues to involve academics from a variety of disciplines [30]. De Byl [28], the team manager for the project, states the need for educators to dabble in 3-D virtual worlds and gaming applications as a method to promote interactive learning. The open, non-proprietary AliveX3D program is based on the Web 2.0 ethos of social networking and exemplifies the creation of a Web 2.0-Web3D hybrid platform which is "interoperable" and contains reusable 3D learning objects with an overall intention of "1) the re-use of data sources; 2) cost-effective scalability; 3) user controlled data; and 4) collective intelligence with respect to the e-Learning possibilities" (p. 6) [28]. Furthermore, when compared to the proprietary 3-D environments of SL and Active Worlds, AliveX3D, as an e-Learning application, has the capacity of being extended and allows educators the opportunity to control the content. It is relatively inexpensive to install and use because there are no licensing fees attached to the program [28].

Who would imagine attending medical school in a virtual world? For many years healthcare educators have developed online learning opportunities for medical and nursing students. Stott

[33] reports universities are turning to SL's virtual world and encouraging students to "fly" into 3-D lecture halls as "cybergoths." Problem-based learning groups enrolled in a clinical management course at Coventry University meet in SL and are employed to build learning facilities for the next semester of SL students. This management course teaches students to manage healthcare facilities and is reported to be the first healthcare-related class to use SL as a learning environment. Another example of a medical school using SL is St. George's Medical School in London. The technology enables students to interact with patient avatars in a simulated world and, moreover, students from around the globe may listen to invited guest lecturers in SL. The novel idea of combining medical simulation with gaming technologies is happening, and collaborators at Forterra Systems and the Summit group at Stanford University medical school are developing human avatars which exhibit life signs with the hope the learner's active participation will encourage awareness, team cooperation, and decision-making skills [15].

Another virtual world project developed by staff at the Imperial College in London, in collaboration with the National Physical Lab in the United Kingdom, is the Second Health Project [34]. A detailed hospital comes to life in SL when physicians, writers, videographers, animators, designers, and builders gather together to create a fully equipped high technology system of healthcare that primarily focuses on health promotion while providing some detailed animations that simulate disease processes, such

as heart attacks and other medical conditions. The community hospital is designed to represent real life in a modern UK city. Currently, the hospital is used for medical and other healthcare-related training. Mesko [35] presents the top 10 virtual medical sites in SL. For example, the Ann Myers Medical Center in SL is an environment where medical students may practice conducting physical exams and analyse radiological films, as well as learn how to detect heart defects. Boulos [36] developed The Sexual Health SIM in Second Life. Avatars may interact with different objects in an aesthetic "in-world"

environment and learn about safe sex and sexual health topics (Figure 3).

The development and use of 3-D virtual worlds in nursing education is increasing. For example, students may learn how to provide step-by-step care for a patient suffering from chest pain via SL [1]. According to Miller [1], students build SL "objects" to show what they have learned. Furthermore, students collaborate with other students from different countries and other medical professionals. Miller uses "Centralia" island in SL as a place to teach nursing students (Figure 4).

Figure 3. Maggie Waechter (the avatar of the author) visiting the Sexual Health SIM in Second Life [36]

Figure 4. A screenshot of objects representing lungs in nursing education [37]

Objects representing lungs connected to large airway objects illustrate various lung disorders for student learning. Miller claims the 3-D objects, representing body parts, are easy to create. Learning objectives are provided for the students visiting "Centralia", and critical-thinking questions are posed along with the anatomical objects. The student's avatar may walk on different electrocardiogram (ECG) tracings on a 3-D floor and then names the represented rhythm. This is an example of immersive interactive learning. The site allows students to view objects in SL together and discuss different medical conditions in a team approach.

Another example of a cognitive, experiential 3-D learning tool is PULSE!! [38]. Researchers at PULSE!! state students respond positively to using the virtual world as a method to learn clinical skills and increase diagnostic thought processes. Of those polled, 80% of the participants stated the platform captured their interest, and 82% expressed positive thoughts about using PULSE!! The Office of Naval Research funds the program and Congress has appropriated more than US $12 million dollars to the project's sustainability.

Practical and Useful Theories Expressed for the Use of 3-D Learning Environments

Roger's Diffusion of Innovations Theory

When an academic or learner is introduced to a specific innovation which may influence their intellectual prowess, an assumption may be made that the innovation has inherent characteristics, such as the creation of opportunities for enhanced learning, versatility, simplicity, and enhanced, self-regulated learning. Many academics are time poor, and the thought of mastering a new e-learning tool, purported to enhance student learning, may create more stress. Barriers begin to develop between the educator and the new learning tool because there is a lack of time to learn and understand how to use the new tool. Often there is very little evidence of positive outcomes when an innovation is newly introduced. The advantages of the new technology may be introduced; however, the "why," "what," and "what about" questions regarding the innovation need to be answered in order for the technology to be accepted, experimented, and adopted. Rogers [5] explains five attributes having an effect on an individual's decision to adopt an innovation. These include a) the relative advantage of the innovation over an idea that it supersedes; b) compatibility, or how does the innovation meet the needs of potential adopters; c) complexity, or how difficult the innovation is to understand and use; d) trialability, or how the innovation may be tested in

a timely fashion; and e) observability, or, in other words, the outcomes associated with the innovation are visible to others.

Grant foundations and university development funds have supported the development costs associated with educational virtual worlds [39]. Wright states the development costs for a SL virtual campus is approximately US $25,000 if constructed by a commercial agency [39]. Even though there is an increased demand for gaming, animation, and 3-D visual spaces in higher education, there needs to be clear explanations to students, academics, and employers, about the benefits associated with virtual worlds. Professional skills, such as reasoning, teamwork, and role playing, will need to be transferred to the workplace before adoption is easily accepted [17,29].

Historically, 3-D learning-environment development required complex and highly involved elements of software engineering and computer science [40]. For many educators, an online 3-D learning environment would not be perceived as being an advantage because the "plasticity" associated with the virtual worlds—or, in other words, the ease of constructing and changing the learning environment as necessary would not be understood until the educator played and experimented with the virtual worlds [27]. The valuable communication tools built into the 3-D system, and the ease associated with the learning area to provide guidance and assistance, may not be fully realized. In addition, some educators still do not see e-learning beyond learning management systems and have not had exposure to virtual worlds (eg, played in them). Therefore, a low compatibility issue presents itself in the academic milieu. Rogers [5] explains three types of decisions associated with adopting an innovation: a) the system is "optional" and the individual may adopt or reject the technology being considered, b) the collective group makes a decision to adopt or reject the technology, or c) one individual in authority makes the decision with the idea the group will follow that decision. These types of decisions have a large impact on the individual adopter and the outcome for the social system as a whole. However, the tides are currently changing with Google Corporation's release of "Lively" [40], in which individuals can easily create their own avatar and personal room to embed at a location of choice on the Web (eg, blog, social network site, or Web page). Google's goal is to create a massive virtual world where Google account holders' avatars may visit at any time and interact with one another. Perhaps educators may use this new social network tool to create class "rooms" and take advantage of the ability to embed YouTube videos on virtual plasma screens. Perhaps the idea of creating a 3-D learning environment may no longer be perceived as a daunting task due to Web 2.0 advanced technologies.

Siemens Connectivism: A Learning Theory for the Digital Age

Siemens' [6] Connectivism Learning Theory is about the formation of "connections" and how, from these connections, a building of "networked" learning occurs. Individuals are continuously forming social networks and are being acted upon, or act upon, while moving in and out of these networks. "Living life" is a dynamic learning process, and we are constantly developing new connections, moving toward larger networks

or breaking down into smaller groups, as we interact with one another. Furthermore, the means of adapting and learning while interacting with the world around us are ever changing. Learning theories attempt to explain the complexity of learning, and many educators are moving away from the static knowledge development or the "destination" of knowledge and are embracing a paradigm shift that is one of "a process of walking in varying degrees of alignment with a dynamic environment" (p. 1) [6]. Therefore, connectivism dovetails nicely with the thesis of virtual 3-D learning environments being supportive of communication, community, and sharing. Communication is an aspect of effective teamwork, while another important aspect of teamwork that is essential in healthcare and education is "how" members interact with each other or develop connections that form a community of practice. Hobbs, Brown, and Gordon [40] state the benefits associated with developing communities of practice within virtual world environments in order to transfer skills that will enhance collaborative work within the work environment. Moreover, there exists a commonly held belief students will feel more satisfied with their course work if they are involved and continue to develop relationships with their peers in learning environments. Virtual world environments allow for the transfer of skills from virtual worlds to the work place and perhaps the development of lifelong skills.

Strengths Associated with 3-D Virtual Worlds

Virtual worlds have been portrayed in film and literature for many years and may play a role in education, business, and healthcare education because this technology may change the way people learn and live in the future [13,17,29]. The major strengths associated with virtual worlds are one's ability to design and construct unique environments and then share them with others in a collaborative fashion. Educators may write specific learning goals for students to complete while learners actively build and interact in environments that promote creativity and social networking. Sibbet [21] outlines how virtual worlds are "reshaping" learning, communications, social interactions, and perceptions. Furthermore, Sibbet presents interesting questions surrounding themes, such as cross-generational communications, identity exploration, cross-cultural exchange, problem solving, deep dialogue, and ceremony. All of these questions have implications for healthcare professional development and education, and even healthcare delivery.

Since an online virtual world is available 24/7 there is an anytime/anywhere benefit for distance education students. There are other advantages, such as virtual training approaches that yield results and are invaluable for healthcare professionals, and, for the healthcare consumer, there is an advantage of logging on and learning from events happening in SL, such as the 2006 health fair. This is especially useful if the individual is at a physical distance. The medium is excellent for improving students' access to places otherwise difficult to reach. The technology makes spatial representation useful for hands-on learning and heightened student engagement because the

real-time social interaction and gaming aspect spurs chances for "discovery-based and goal-oriented learning" [29].

Challenges Associated with 3-D Virtual Worlds

With any innovative technologically supported pedagogical tool there are critics who debate the usefulness of the application [4]. However, one recalls when critics questioned the validity and reliability of the stethoscope invented by Laennec in 1816 and how today it is second nature to use this assessment tool. Hence, using virtual simulations to teach healthcare students may be questionable until more research is conducted and educational outcomes are realized. Two of the major challenges associated with virtual worlds in education is the time involved in creating learning spaces within a virtual environment, as well as the cost involved. Blake argues since virtual world games are played in real time, the flexibility of distance-learning tools is not realized. The efficiency associated with sharing text, images, and videos via an avatar versus a standard format on a computer's desktop is questionable (Adam Blake, written communication, October 19, 2007). A negative human response to other avatars in the learning environment is possible; however, this may exist in traditional learning settings as well. The allure of the dynamic colourful SL environment may distract the student's attention from the learning objectives. Of course, these are all points of view that may be debated. Clearly empirical research is needed for future use of virtual worlds in healthcare training and general education. Striking challenges facing developers of virtual worlds and serious gaming for educational purposes are ownership of collaborative work and certification of authorship. Both of these issues pose a problem for evaluation for learning outcomes [29].

Research Efforts

Educational research regarding 3-D virtual worlds and the effects on learning outcomes is lacking. However, Bainbridge [13] states scientists and scholars are moving forward in conducting research about virtual worlds and encourages this research be completed in a timely manner because the current transformation of the virtual worlds is time sensitive, and future retrieval may be challenging. Ackermann, as stated in Schneider [41], explains interactivity is a key to learning. "An increasing number of software designers, cognitive scientists, and educators have come to the view that experience is actively constructed and reconstructed through direct interaction with the world, and that, indeed, knowledge is experience" (p. 1) [41]. Byrne [42] conducted a pre- and post-experimental study examining the use of Virtual Reality (VR) as an educational tool and discovered high-school students' (N=38) knowledge of atomic and molecular structures before and after a VR experience was significant for "interactivity" but not for "physical immersion." Statistical results for the aforementioned study were not presented. Chapman, Stone, and Nelson [43] indicate that providing simulations in 3-D virtual learning environments presents the potential of enhanced learning. Increased interactivity with the learning material, provision of self-directed and immersive learning experiences, and students' co-creation

of learning content with other students and the instructor are cited in the literature [43]. The same researchers [43] explain simulations and case-based scenarios build upon well-defined educational theories, such as constructivism, experiential learning, adult learning theory, social presence, and situated learning. The considerations determined by researchers are: a) resources to develop the virtual worlds, b) available technical support, c) ethical considerations, d) accessibility, e) usability concerns, f) ownership of content, and g) peer review. More research is needed to determine students' satisfaction, competency, and knowledge acquisition.

Vision for Future Use in Medicine and Healthcare Professional Education

One may view online virtual worlds and serious gaming as a threat to the adoption and purchase of high-fidelity computerized patient-simulation mannequins that are currently purchased for healthcare-profession training. For example, nurses may login into SL and learn Advanced Cardiac Life Support at their convenience, and it costs virtually nothing for the nurse and perhaps a nominal fee for the developer. Why would an educator want to recreate or even offer such a training opportunity when it already exists on the Internet? Of course, one could argue that it lacks a haptic quality essential for the procedure or lacks one-on-one assessment of skill acquisition. The educational opportunity in SL may not be a replacement for the doctor- or nurse-patient interaction or relationship, but SL may serve as an adjunct or pre- or post-learning tool. The advisory board responsible for Educause's Horizon Report [29] states collaborative learning experiences taking place in virtual worlds today are easier to find than a year ago when the authors predicted virtual worlds being one to two years away from adoption.

Discussion

Critical challenges associated with the development, adoption, and evaluation of online virtual worlds for healthcare training education do exist. However, there is an underlying push in higher education to adopt these collaborative tools and shift the paradigm from a traditional Socratic method of education to one possessing a more active and interactive nature [29]. Virtual worlds are a part of our present existence and offer online users of all ages opportunities to explore, create, imagine, collaborate, role play, interact, socialize, learn, and experience moments in a safe and vivid manner. What better way to learn than when you are having fun and actively participating in making choices, decisions, and interacting with others in a safe space? Let's look forward and determine research methodologies, such as experimental or qualitative design, to evaluate the relevance of virtual worlds for teaching, learning, and creative expression. Research will substantiate factors we suspect have an influence on a learner's ability to retain and search for and retain knowledge. The educator is in a position to look at who the learners are and what the learners really want from their learning experiences. What motivates generations Y and Z to learn? What are they accustomed to doing on a daily basis? Why not research, investigate, and try this social networking and virtual

reality tool and create learning moments in what may really be a "now" in-world?

Conclusion

Virtual 3-D learning environments may encourage active learning while students create and explore activities similar to those of a "field trip", versus the experience of a static classroom setting. This reaching out and meeting new avatars and practicing communication skills in an aesthetic environment may help maintain today's students' interest in learning and provide valuable experiences that may enhance student engagement, promote participation, and motivate self-directed learning. Educators that see "on-the-horizon technologies" in higher education present an opportunity for today's learners to explore exciting worlds beyond the traditional classroom and are showing an understanding of current students' use of technology. Moreover, participating or playing in a virtual world may be enjoyable for the learner, encourages creative expression, broadens socialization skills, promotes independent problem solving, provides opportunities for self-teaching, and

sets the stage for group work. There are established opportunities for educators to network with alliances that are already developing, implementing, and researching 3-D virtual worlds as learning spaces [1,21,27,28,38]. Therefore, the wheel of technology does not need to be reinvented by individual educators because, as outlined in this paper, there are opportunities for educators to meet like-minded individuals. Empirical research findings will help determine if learning objectives are met by offering this type of educational tool. Some educators may balk at adopting this technology because there is a learning curve associated with the use of 3-D virtual worlds. It is noteworthy to understand the necessity to educate the educator in order to bring that willing individual up to speed on how to operate the 3-D virtual world. However, there are some very current Web 3-D programs, such as Lively [40], that may decrease the learning curve and motivate the educator to develop class "room" spaces. Let's have fun, explore these fascinating worlds and games, and network with others while respecting diverse ways of life-long learning and current researchers' findings.

Conflicts of Interest

None declared.

Multimedia Appendix

From Computer Based Simulations to 3-D Virtual Learning: Building Bridges to Collaborative Learning Spaces

[PPT file (Microsoft Powerpoint File), 3.4 MB - jmir_v10i3e26_app1.ppt]

References

1. Miller J. Virtual Medical Projects Besides Second Life. Blogger. URL: http://jsvavoom.blogspot.com/ [accessed 2008 Jul 7] [WebCite Cache ID 5Z94mXeF9]
2. Hansen M, Murray P, Oyri K. Health informatics 2.0/3.0 and beyond: how evocative networks are transforming health and education (panel presentation). 2008 May 25-28 Presented at: MIE2008: eHealth beyond the horizon, Get IT there; Gothenburg, Sweden.
3. Murray P, Moura LA, Cabrer M, Hammond WE, Hansen M. IMIA and Web 2.0: exploring the potential for integration into international health informatics (panel presentation). 2008 May 25-28 Presented at: MIE2008: eHealth beyond the horizon, Get IT there; Gothenburg, Sweden.
4. Hansen M. Online virtual 3-D healthcare learning environments (presentation). 2008 Feb 12 Presented at: First Education Meeting. Health Informatics Society of Australia, New South Wales; Sydney, Australia.
5. Rogers EM. Diffusion of Innovations, 5th edition. New York, NY: Free Press; 2003.
6. Siemens G. Connectivism: Learning as Network Creation. elearnspace. URL: http://www.elearnspace.org/Articles/networks.htm [accessed 2008 Jul 12] [WebCite Cache ID 5ZFdi7nHV]
7. Jutecht. You Tech Tips. Understanding Web 2.0. YouTube. URL: http://www.youtube.com/watch?v=nsa5ZTRJQ5w [accessed 2008 Jul 8] [WebCite Cache ID 5ZAIwycUk]
8. Murray P. Web 2.0 and Social Technologies: What Might They Offer for the Future of Health Informatics? HealthCare and Informatics Review. URL: http://hcro.enigma.co.nz/website/index.cfm?fuseaction=articledisplay&FeatureID=010608 [accessed 2008 Jul 9] [WebCite Cache ID 5ZC4MEur7]

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9.   Eysenbach G. Medicine 2.0 Congress Website Launched (and: Definition of Medicine 2.0 / Health 2.0). Gunther Eysenbach's Random Research Rants. URL: http://gunther-eysenbach.blogspot.com/2008/03/medicine-20-congress-website-launched.html [accessed 2008 Mar 7] [WebCite Cache ID 5W9GcYyWN]

10. Baretto C. What Comes After Web 2.0? XML 2007 Conference and Exposition. URL: http://2007.xmlconference.org/public/schedule/detail/448 [accessed 2008 Jul 9] [WebCite Cache ID 5ZC5DdRMN]

11. Second Life. URL: http://secondlife.com [accessed 2008 Jul 11] [WebCite Cache ID 5ZEvRSNLx]

12. Boulos MNK, Hetherington L, Wheeler S. Second Life: an overview of the potential of 3-D virtual worlds in medical and health education. Health Info Libr J 2007 Dec;24(4):233-245. [Medline: 18005298] [doi: 10.1111/j.1471-1842.2007.00733.x]

13. Bainbridge WS. The scientific research potential of virtual worlds. Science 2007 Jul 27;317(5837):472-476 [FREE Full text] [Medline: 17656715] [doi: 10.1126/science.1146930]

14. Pellerin C. U.S. Government Presence Grows in Second Life Online World. Embassy of the United States. URL: http://tokyo.usembassy.gov/e/p/tp-20070509-04.html [accessed 2008 Jul 13] [WebCite Cache ID 5ZITdWKl7]

15. Kusumoto L, Shorrock D, Heinrichs WM, Dev P, Youngblood P. The integration of physiology models with avatars to expand the opportunities for high-fidelity medical training. 2007 Presented at: SimTech 2007 Healthcare Simulation Conference p. 50-53.

16. Morin A, Benhamou AC, Spector M, Bonnin A, Debry C. The French language virtual medical university. Stud Health Technol Inform 2004;104:213-219. [Medline: 15747982]

17. ; New Media Consortium and the Educause Learning Initiative. The Horizon Report 2007 Edition. .

18. There. URL: http://www.there.com [accessed 2008 Jul 11] [WebCite Cache ID 5ZEx1bbxY]

19. Active World. URL: http://www.activeworlds.com [accessed 2008 Jul 11] [WebCite Cache ID 5ZExMlhCo]

20. ; Second Life Teleport. Ann Myers Medical Center, Sprott Shaw College. In-world 2008 Aug 13 .

21. Sibbett D. Second Life Retrospective. Sunseed Bardeen in Deimos Studio. davidsibbett.com. URL: http://www.davidsibbet.com/david_sibbet/2007/11/second-life-ret.html [accessed 2008 Jul 11] [WebCite Cache ID 5ZF0SxHip]

22. Move Me! Interactions on Movement and Emotion in SL Course Design. New Medium Consortium (NMC). URL: http://www.nmc.org/vodcast/cynthia-calongne-move-me [accessed 2008 Feb 13] [WebCite Cache ID 5Vapu4QWx]

23. Wii. URL: http://wii.com [accessed 2008 Jul 11] [WebCite Cache ID 5ZF05fo7U]

24. Tanner L. Doctors Use Wii Game for Rehab Therapy. Associated Press. URL: http://www.military.com/entertainment/games/game-news/doctors-use-wii-games-for-rehab-therapy [accessed 2008 Jul 11] [WebCite Cache ID 5ZEzxqbP0]

25. Oishi L. Surfing Second Life: what does Second Life have to do with real-life learning? (virtual world). Tech and Learning 2007 27(11):54 .

26. MacManus R. Semantic Wave 2008—Free Summary Report for RWW Readers. ReadWriteWeb. URL: 2008 Jul 11 [accessed 2008 Jul 11] [WebCite Cache ID 5ZF0oLuAk]

27. Ramloll R. The Power of Play: Real-Life Experts Meet in a Virtual World to Prepare for Disaster. Socialtext. URL: http://www.socialtext.net/play2train/index.cgi?relevant_articles [accessed 2008 Jul 12] [WebCite Cache ID 5ZFeyXaSa]

28. de Byl P, Taylor J. A Web 2.0/Web3D Hybrid Platform for Engaging Students in E-Learning Environments. Turkish Online Journal of Distance Education. URL: http://tojde.anadolu.edu.tr/tojde27/articles/article_7.htm [accessed 2008 Jul 11] [WebCite Cache ID 5ZF4QxGDT]

29. ; New Media Consortium and the Educause Learning Initiative. The Horizon Report 2008 Edition 2008 Jan 31.

30. ALIVE. Advanced Learning and Immersive Virtual Environment. URL: http://www.alivex3d.org/default.htm [accessed 2008 Jul 11] [WebCite Cache ID 5ZF33nA9y]

31. ALIVE Classmate. Advanced Learning and Immersive Virtual Environment. URL: http://www.alivex3d.org/classmate.htm [accessed 2008 Aug 13] [WebCite Cache ID 5a3NKRuDl]

32. ALIVE DX Editor. Advanced Learning and Immersive Virtual Environment. URL: http://www.alivex3d.org/editor.htm [accessed 2008 Jul 11] [WebCite Cache ID 5ZF3Srwua]

33. Stott D. Attending Medical School in Virtual Reality. Student BMJ. URL: http://student.bmj.com/issues/07/12/news/431.php [accessed 2008 Jul 12] [WebCite Cache ID 5ZFgvW1yB]

34. The Future of Healthcare Communication. Second Health. URL: http://secondhealth.wordpress.com [accessed 2008 Jul 12] [WebCite Cache ID 5ZFh57yT0]

35. Mesko B. The Top Ten Medical Sites in Second Life. Science Roll. URL: http://scienceroll.com/2007/06/17/top-10-virtual-medical-sites-in-second-life [accessed 2008 Jul 12] [WebCite Cache ID 5ZFhLxYcB]

36. Boulos MNK. The Sexual Health SIM in Second Life. University of Plymouth, Devon, UK. URL: http://healthcybermap.org/slsexualhealth [accessed 2008 Aug 13] [WebCite Cache ID 5a3PN5yon]

37. Miller J. Video of Centralia Island in Second Life. Blogger. URL: http://jsvavoom.blogspot.com [accessed 2008 Aug 13] [WebCite Cache ID 5a3QCIgIE]

38. The Virtual Clinical Learning Lab. PULSE!!. URL: http://www.sp.tamucc.edu/pulse/home.asp [accessed 2008 Jul 11] [WebCite Cache ID 5ZF7Mjae2]

39. Wright T. Second Life Education: Second Life as a Virtual Learning Environment. dokimos.org. URL: http://www.dokimos.org/secondlife/education [accessed 2008 Jul 8] [WebCite Cache ID 5ZANUxCoV]

40.   Aune S. Virtual Worlds: 20+ Tools for Creating 3D Graphics and Environments. Mashable.com. URL: http://mashable.com/2008/07/10/tools-for-3d-creation [accessed 2008 Jul 11] [WebCite Cache ID 5a9Mub1th]

41.   Schneider DK. Virtual Environments for Education, Research and Life. TECFA (Technologies de Formation et Apprentissage). URL: http://tecfa.unige.ch/moo/paris96/papers/daniel.html#SECTION0003000000000000000 [accessed 2008 Jul 11] [WebCite Cache ID 5ZFICe9eE]

42.   Byrne CM. Water on Tap: The Use of Virtual Reality as an Educational Tool. Human Interface Technology Lab (HITLab). URL: http://www.hitl.washington.edu/publications/dissertations/Byrne [accessed 2008 Jul 11] [WebCite Cache ID 5ZFIv30ze]

43.   Chapman DD, Stone SJ, Nelson D. From Computer Based Simulations to 3D Virtual Learning: Building Bridges to Collaborative Learning Spaces. URL: http://www.google.com/search?q=Chapman+Stone+and+Nelson+simulations&ie=utf-8&oe=utf-8&aq=t&rls=org.mozilla:en-US:official&client=firefox-a [accessed 2008 Jul 11] [WebCite Cache ID 5ZFJkFubR]

Abbreviations

3-D: three-dimensional
ALIVE: Advanced Learning and Immersive Virtual Environment
MMOG: Massively Multiplayer Online Game
MMVW: Massively Multiplayer Virtual World
SL: Second Life

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Viewpoint

A Second Life for eHealth: Prospects for the Use of 3-D Virtual Worlds in Clinical Psychology

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Abstract

The aim of the present paper is to describe the role played by three-dimensional (3-D) virtual worlds in eHealth applications, addressing some potential advantages and issues related to the use of this emerging medium in clinical practice. Due to the enormous diffusion of the World Wide Web (WWW), telepsychology, and telehealth in general, have become accepted and validated methods for the treatment of many different health care concerns. The introduction of the Web 2.0 has facilitated the development of new forms of collaborative interaction between multiple users based on 3-D virtual worlds. This paper describes the development and implementation of a form of tailored immersive e-therapy called p-health whose key factor is interreality, that is, the creation of a hybrid augmented experience merging physical and virtual worlds. We suggest that compared with conventional telehealth applications such as emails, chat, and videoconferences, the interaction between real and 3-D virtual worlds may convey greater feelings of presence, facilitate the clinical communication process, positively influence group processes and cohesiveness in group-based therapies, and foster higher levels of interpersonal trust between therapists and patients. However, challenges related to the potentially addictive nature of such virtual worlds and questions related to privacy and personal safety will also be discussed.

Introduction

Since the introduction of the Web 2.0 in 2004 [1], there has been a huge increase in the potential of Web applications, allowing users to create, modify, and share contents using multiple computers in various locations. The Web 2.0 is a read-write Web that facilitates social networking, collaboration, and participation between users [2,3]. One hugely successful application of the Web 2.0 is represented by three-dimensional (3-D) virtual worlds (eg, Second Life [4], There [5], and Active Worlds [6]). These computer-based, simulated environments are characterized by the simultaneous presence of multiple users who inhabit and interact via avatars within the same simulated space. The computer-simulated world typically appears similar to the real world, with real world rules such as gravity, topography, locomotion, real-time actions, and communication. Over the last few years, the number of virtual world users has increased dramatically, and today, Second Life, the largest 3-D online digital world, boasts some 12 million subscribers. 3-D virtual worlds can be considered as 3-D social networks, where people can collaborate to create and edit objects (like a collaborative 3-D wiki space) besides meeting each other and interacting with existing objects. Compared with the conventional Web 1.0 applications, virtual worlds offer novel ways to develop social skills; socialize and interact with other people via customizable, realistic, 3-D, fully textured, and

animated avatars; attend and participate in live events like lectures and conferences; build communities, including learners' communities and patient support groups; relax and visit new places; and browse document collections in 3-D virtual libraries. 3-D virtual reality (VR) worlds also show great potential for health purposes. In particular, Second Life currently features a number of medical and health education projects. By way of example, the Nutrition Game proposed by the Ohio University [7,8] simulates choices a user can make in various restaurants and informs the player about the health impacts of those choices. The Heart Murmur Sim [9,10] provides an educational virtual world for cardiac auscultation training that enables clinical students to tour a virtual clinic and test their skills at identifying the sounds of different types of heart murmurs. The Second Life Virtual Hallucinations Lab [11,12] aims to educate people about schizophrenic hallucinations. The Gene Pool [13] is an interactive genetics lab and learning area featuring simulated lab experiments, tutorials, and simple videos to enhance the learning experience. The Virtual Neurological Education Centre (VNEC) [14] demonstrates a virtual simulated online experience where people are able to actively expose themselves to the most common symptoms that a person suffering from a neurological disability may encounter, and the HealthInfo Island [15] is funded by the US National Library of Medicine (NLM) to provide consumer health information services. All of these virtual initiatives are mainly centered on the promotion of an innovative form of public health consisting of the diffusion of medical information and the education of therapists and patients [16].

The aim of the present paper is to introduce and discuss the use of 3-D virtual worlds for an innovative online health service called p-health. P-health provides personalized immersive e-therapy whose key factor is interreality [17], ie the creation of a hybrid-augmented experience merging the physical and virtual world. In p-health, the interreality experience is achieved through the following:

- an extended sense of presence [18-20]: P-health uses advanced simulations (3-D virtual worlds) to transform health guidelines and provisions into experience. In p-health, users do not receive abstract information but live meaningful experiences.
- an extended sense of community (social presence): P-health uses hybrid social interaction and dynamics of group sessions to provide each user with targeted—but also anonymous, if required—social support in both the physical and virtual world.
- real-time feedback between the physical and virtual worlds: P-health uses bio and activity sensors and devices (eg, PDAs, mobile phones) to track both the behavior and the health status of the user in real time and to provide targeted suggestions and guidelines. The feedback activity is twofold: (1) behavior in physical world influences the experience in the virtual one (eg, if I eat too much and I do not exercise, my avatar will become fatter), and (2) behavior in the virtual world influences the experience in the real one (eg, if I participate in the virtual support group, I can exchange SMS messages with the other participants during the day).

Our hypothesis is that the introduction of the p-health approach in eHealth services could extend the potential of the Web 2.0 and shared 3-D worlds to therapists and patients. To support this claim, the paper will describe how the use of avatars can improve social presence. Further, we will focus on the existing applications of 3-D worlds in clinical settings and address some ethical considerations and possible pitfalls of using 3-D worlds for therapeutic purposes. Finally, we will introduce a possible p-health scenario we are developing in Second Life for the treatment of addiction disorders.

Psychological Features in Avatar-Based Interaction

The p-health approach suggests that providing remote patients with a feeling of social presence [21] plays a crucial role in improving therapeutic effectiveness. Through social presence, users experience a feeling of inhabiting a shared space with one or more others, and their awareness of mediation by technology recedes into the background [22]. Social presence requires participants to experience themselves as co-located and mutually aware of, responsive to, and responsible to one another [23]. As suggested by Casanueva and Blake [24], the sense of social presence consists of the belief that the other people in the virtual environment are real and really present and that the user and the others are part of a group and process.

We suggest that 3-D virtual worlds are able to convey strong feelings of social presence through avatar interaction, enhancing the feeling of togetherness of remote users who are connected through some form of telecommunication medium. Results of recent studies about avatar-based social interaction lend support to this hypothesis [25]. In their research, Bente and colleagues [26] measured social presence and interpersonal trust in avatar-based collaborative net communications, comparing this condition with face-to-face communication as well as with audio-based (phone) and text-based Web communication. The results from 48 participants showed that the level of co-presence was higher in avatar-based interactions than in phone or chat interactions. In a subsequent study, Bente and colleagues [27] investigated the experience of social presence as a relevant effect dimension of avatar-mediated Web communication. A total of 142 participants were randomly assigned to one of five possible communication settings: (1) text only, (2) audio only, (3) audio and video, (4) audio and low fidelity avatar, (5) audio and high fidelity avatar. Results revealed a significant difference between text and all other communication modes, indicating that audio, video, and avatar systems work similarly and better than text alone in creating the experience of social presence. However, according to the authors, avatar platforms offer new potentials to overcome many of the restrictions related to audio and video communication modes. In particular, they suggest that virtual worlds and avatars play a critical role in contextualizing social interaction and fostering the salience of nonverbal information by providing active filtering and contingency management systems as opposed to being just the virtual equivalents of a video conferencing system.

Other studies have suggested that even avatars with rather primitive expressive abilities may elicit strong emotional

responses in users sharing a collaborative virtual environment. Experiments have shown that the avatar can readily take on a personal role, increasing the sense of community feeling and becoming a genuine representation of the underlying individual, not only visually, but also within a social context [28]. Moreover, Yee and colleagues [29] investigated whether norms about social space in the real world map onto how avatars act in relation to each other in virtual space. In an observational study, the authors collected data from avatars in order to explore whether social norms of gender, interpersonal distance (IPD), and eye gaze transfer into virtual environments even though the modality of movement is entirely different. They found that, as in the real world, male-male dyads tend to stand further apart and look at each other much less than female-female dyads: (1) male-male dyads have larger IPDs than female-female dyads, (2) male-male dyads maintain less eye contact than female-female dyads, and (3) decreases in IPD are compensated with gaze avoidance. In summary, all these preliminary findings suggest that avatar-based interaction in virtual worlds may have the potential to enrich the level of emotional connections and social presence conveyed by conventional telehealth tools, such as Internet, videoconferencing, email, and telephone.

From a clinical perspective, the advantages presented by the 3-D, avatar-based interactions serve to facilitate the communication process between therapists and patients, to positively influence group cohesiveness in group-based therapies and to create greater levels of interpersonal trust, which is a fundamental requirement to establish a successful therapeutic alliance.

3-D Virtual Worlds As a Support Tool for Psychological Interventions

The strong sense of presence and social connection elicited by avatar interaction suggests two possible clinical applications of 3-D virtual worlds. The first regards the potential to provide VR-based treatments within the online virtual worlds, and the second regards the creation of online virtual communities of patients.

3-D Virtual Worlds and Virtual Reality Exposure Therapy

In recent years, a number of studies have suggested the efficacy of VR exposure therapy in the diagnosis and treatment of various psychological disorders. Positive results have been obtained in the treatment of specific phobias (in particular, aviophobia, acrophobia, fear of driving, claustrophobia, and arachnophobia), eating disorders, social anxiety disorders, sexual disorders, posttraumatic stress disorder, and panic disorder with or without agoraphobia [30,31].

During the VR exposure, the patient is immersed in a virtual environment containing the critical stimulus. This procedure, which has been shown to be at least as effective as traditional techniques in reducing phobic symptoms [32], presents some practical advantages offered by the use of VR technology. As stimuli are computer generated, the therapist has full control over their intensity, and the risk of unpredictable effects is significantly lower than in vivo exposure since subjects have

the opportunity to explore threatening aspects of reality in a safe environment where consequences are not real [33]. Further, virtual exposure provides an opportunity to present the patient with realistic 3-D visualization of the feared situation, which is more effective than imagination, especially when the patient is unable to recreate the critical scenarios because of pathological avoidance of problematic memories, as is often the case in posttraumatic stress disorder [34]. When used in combination with specific instruments, the VR exposure has the added advantage of allowing therapists to record different psycho-physiological parameters before, during, and after exposure to the feared stimuli in order to obtain objective measures of the individual modifications.

3-D virtual worlds appear to have much to offer to exposure therapy of this kind. The therapist and patient share the same online virtual space and, in this way, the therapist can accompany the patient through a particular threatening experience just by logging onto a specific website and adopting a preferred avatar. Interaction can be modified on the basis of therapeutic needs. In the case of social phobia, for example, after practising with the therapist within a closed environment (ie, the therapist's virtual office), the patient can be taken to a virtual world populated by other avatars and asked to initiate a conversation and obtain feedback from them in real-time audio through the use of a microphone. Similarly, patients with agoraphobia can be exposed to a variety of unfamiliar worlds different from those the clinician can provide in an office setting. Patients suffering from addiction disorders (eg, drug abuse, pathological gambling, food craving) can be exposed to specific kinds of dangerous stimuli without running the risk of "succumbing to temptation" [35].

3-D Virtual Worlds for Creating Virtual Communities of Patients

3-D virtual worlds may have the potential to bring several innovative features to virtual patient communities by providing mediated environments with appropriate social, nonverbal, and contextual information that previous Web applications (Web 1.0) were unable to convey. Winkelman and Choo [36] surmised that patients with chronic diseases possess a particular tacit knowledge gleaned from their personal experience of illness and experientially acquired by having to cope with the daily challenges and needs posed by a chronic disease. These needs include information on the disease, treatment side effects, treatment plans, professional contacts, as well as supportive information for family and friends. According to the authors, if this tacit knowledge can be shared or socialized through a program, tool, or medium, a patient's sense of self-efficacy can improve, thereby positively affecting health outcomes as well as social functioning. This approach argues for a shift in the role of chronic disease patients from external consumers of health care services to a community of practice of internal customers. Introduced by Wenger (1998), communities of practice are social constructs that bring learning into lived experience of participation in the world [37]. They are defined as self-organizing, informal groups whose members work together toward common goals, face common needs, share best practices, and have a common identity. Drawing on these concepts, Winkelman and Choo [36] suggest that with the

implicit support of health care organizations, patients can benefit from gaining access to the expertise of peers by integrating knowledge gained from the experiences of living with chronic disease into their self-management. In particular, they claim that virtual patient communities can become effective tools of communication if (1) members have common interests, needs, goals, as well as an aspiration for mutual communication and the furthering of relationships, and (2) they are able to supplement already existing face-to-face communication opportunities. Even in this case, the possibility to share specific virtual environments from different parts of the world and to interact via customizable avatars can presumably facilitate the development and the diffusion of online communities of practice allowing an efficient exchange of medical and experiential information between patients and experts.

Existing Therapeutic Applications in Second Life

In this section we will briefly explore some of the Second Life virtual environments specifically created for therapeutic purposes. Inspired by the therapeutic success obtained with different kinds of virtual treatments [38,39], and taking advantage of the potential of the Second Life platform, Brain Talk Industries, the largest nonprofit organization in the world dedicated to providing online communities for patients and caregivers dealing with neurological issues, has created Brigadoon, a private island in Second Life specifically designed for patients with Asperger's syndrome. Brigadoon aims at providing an ideal place for people with a form of high-functioning autism, characterized by enormous difficulties in social interactions, to develop their social skills by interacting with other people dealing with the same problems [40]. After their initial experiences inside Brigadoon, many patients began venturing into Second Life proper and mixing with nonautistic people. Some of them are now active participants in other communities, including two autistic women who have formed "the autistic liberation front," a Second Life space where autistic people can organize, educate, and advocate for themselves [41-43]. A similar aim underlies the creation of Live2Give [44], a Second Life island dedicated to people affected by cerebral palsy. Like Brigadoon, this virtual place brings people together, giving them the possibility to help each other cope with their common struggles. According to Lester, the experience appears to be empowering and revolutionizes the way the users feel about themselves and the part they have to play in the world [45]. Similarly, a British organization called ARCI has developed a virtual environment in Second Life to help abused children learn important life skills. The children enter the virtual world to learn to socialize and work as a team and to learn essential computer skills [46]. A very interesting therapeutic experience related to Second Life is described by Roberto Salvatierra, a medical student suffering from agoraphobia. Within Second Life, he created an avatar that closely resembled his own real-life appearance. By seeing himself in a simulated 3-D environment, Roberto felt he could become more comfortable with unfamiliar open spaces and this was exactly what happened. Thanks to his personal positive experience he decided to set up an in-world group called the "Agoraphobia Support Group," which he hopes other people with agoraphobia will join to discuss their shared difficulties [47,48].

These examples show how 3-D online virtual worlds can provide a richer variety of tools than email or typing text onto bulletin boards, including the opportunity to build new customized environments, create avatars, interact with others without revealing one's real identity (ie, the real physical disabilities one has in the real world), and communicate with people in a way that more closely resembles face-to-face meetings. Moreover, the possibility to buy gestures—animations of avatars making faces—enriches the way in which users can communicate and represent themselves in these experiential virtual worlds. So, even if the main aim of these virtual online communities is to support rather than treat patients, their success proves the potential of 3-D virtual worlds to become very useful tools for an innovative form of eHealth dedicated to patients with mental illness [16,49].

Despite the positive data we have presented, the use of the Internet to provide mental health services is controversial, and, in the ongoing debate about the value and ethics of therapeutic virtual environments, there are proponents at both extremes. Some conceive of technology as means to a bright future where anyone's emotional needs can be instantaneously addressed; others are obstinately opposed to the use of distance psychology for any kind of intervention. In our view, virtual therapy is most effective when it is used as an adjunct to traditional therapy or as part of an aftercare plan. For these reasons, we advise against any kind of therapy being practised exclusively on the Web because of its supportive rather that exhaustive nature. This point must be made clear to online therapy providers and the general public.

Ethical Considerations and Important Caveats in the Use of 3-D Virtual Worlds for eHealth

Although the therapeutic potential of 3-D virtual worlds is quite promising, there are challenges associated with an approach of this kind that need to be addressed. In fact, if it is true that people can explore threatening aspects of reality in a safe environment, it also is true that if the use of online worlds becomes excessive, there is a risk that it will prevent people from forming meaningful real-world relationships. In fact, as observed by Allison et al [33], an increased substitution of cyberspace-based relationships at the expense of face-to-face interaction may create a developmental double-edged sword. In the case of socially anxious patients, for example, the Internet is useful to modify peer group interactions, while it does little to foster the development of genuine intimacy. When exposing patients to virtual environments, therapists should consider the risk of Web addiction and encourage patients to participate in real-life social interaction as much as possible.

Another critical point regards anonymity: the chance to remain anonymous offers a less intimidating opportunity for social interaction and psychological reflection and would allow more people to discreetly seek help on their own. On the other side, anonymity represents a significant risk for patients and

therapists. The computer-based interface does not guarantee that the person on the other side of the screen is really who we expect, and anybody can enter the virtual environment and interact with patients, producing negative effects on their experience and introducing uncontrollable and disturbance variables in the environment. These aspects can be overcome, for example, by creating private servers specific for controlled environments designed and dedicated to therapy and using protection codes personally given by the therapist to the patients.

Regarding the therapists, they need to first conduct self-assessment and then enhance their knowledge and skills in using these alternative forms of therapy [50] since the provision of eHealth services is not simply a click of the mouse [51].

Besides the previous more clinical considerations, there are some very challenging issues that need to be resolved to ensure the safe and ethical use of eHealth in general. These include complex and interrelated questions of security, confidentiality, and privacy; licensure requirements; competency; standards of care; and reimbursement that must be considered by practitioners, researchers, consumers, health care organizations, managed care companies, and federal and state legislatures [52].

The American Psychological Association (APA) has published a statement entitled "Services by Telephone, Teleconferencing, and Internet" [53]. This statement stipulates that in the absence of specific telehealth standards, psychologists must take reasonable steps to ensure competence in providing services and to protect patients, clients, and research participants from harm. The APA is also developing recommendations for the board regarding ethical, legal, and clinical concerns related to the practice of telehealth, with the aim of providing practitioners with information about electronic activities. While conducting interventions via telehealth applications, patients may believe that the Internet sessions are secure and completely private and confidential. To safeguard against a breach in confidentiality, therapists and clinicians should fully inform patients of the limits of confidentiality associated with telehealth and other forms of telecommunications. In sum, the use of 3-D virtual worlds as an advanced form of eHealth holds great promise as long as their limitations and associated risks are taken into consideration as well.

The Use of 3-D Virtual Worlds in Clinical Practice

In the Introduction, we presented p-health as a possible new paradigm for eHealth. From a technological viewpoint, a possible p-health scenario would be based on the following three technologies: 3-D virtual worlds, bio and activity sensors, and personal digital assistants (PDAs) and/or mobile phones. Each will be considered in turn below.

3-D Virtual Worlds

As we have discussed previously, 3-D virtual worlds enable their users to interact with each other through motional avatars. Residents can explore the world, meet other users, socialize, participate in individual and group activities, and buy items (virtual property) and services from one another.

Bio and Activity Sensors (Connection from the Real World to the Virtual One)

Typically 3-D virtual worlds are closed worlds and in no way reflect the real activity and status of the users. In p-health, bio and activity sensors are used to track the health status of users and to influence their experiences in the virtual world (avatar, activity, and access). The link between real and virtual worlds would be in real time, allowing the development of advanced biofeedback settings, but would also ensure health tracking even in situations where an Internet connection is unavailable.

PDAs and/or Mobile Phones (Connection from the Virtual World to the Real One)

In p-health, the social and individual user activities in the virtual world have a direct link with his or her life through a PDA and/or mobile phone. This link is at three levels:

1. follow-up: It is possible to assess and improve the outcome of the virtual experience through the PDA/mobile phone, eventually also using information from the bio and activity sensors.
2. training and homework: Due to the advanced graphic and communication capabilities now available on PDAs/smart phones, they can be used as simulation devices to facilitate the real-world transfer of knowledge acquired in the virtual world.
3. community: The social links created in the virtual world can be continued in the real one even without revealing the real identity of the user; for example, I can send an SMS to a virtual friend in my own real context to ask for support.

It is our view that in p-health the creation of a direct link between the real world experience and the virtual one would serve to improve the accessibility of relevant information, the real-time monitoring of relevant health parameters, the motivation for change, the transfer of acquired knowledge in the real world, the social support, and the availability of anonymous expert guidance.

A Possible Scenario: Addiction

P-health is an approach to health that, in theory, can be used for any kind of health concern. However, to discuss its feasibility, we decided to identify one possible area of intervention: addiction. The term *addiction* indicates a recurring by an individual to engage in some specific activity despite harmful consequences to the individual's health, mental state, or social life. The term was originally reserved for drug addictions, but it is now also applied to other compulsions such as pathological gambling, compulsive overeating, alcoholism, and so on. Addiction is a disease [54], a state of physiological or psychological dependence on something manifesting as a condition in which medically significant symptoms liable to have a damaging effect are present. Treatment of dependency is usually conducted by a wide range of medical and allied professionals, including addiction medicine specialists, psychiatrists, appropriately trained nurses, social workers, and counselors, and is focused on the individual's ultimate decision to pursue an alternate course of action. Behavioral treatments usually involve the planning of specific ways to avoid the

addictive stimulus and therapeutic interventions intended to help a patient learn healthier ways to find satisfaction.

Literature on behavioral analysis and behavioral psychology shows that behavioral therapy, community reinforcement approaches, cue exposure therapy, social skills training, and contingency management strategies are useful approaches for the treatment of addiction [55]. Following these indications, we are developing Eureka [56], a Second Life island for addiction prevention and treatment. Eureka is a virtual immersive environment organized around three different but interconnected areas: the Learning area, the Community area, and the Experience area.

The goal of the Learning area is to use motivation provided by virtual worlds to teach users about how to improve their living habits. The Learning area is organized around different learning areas (Figure 1), both without and with teachers (classes). In this area, users learn how to manage daily choices and activities, acquire general and specific information about addiction, and get the information needed to succeed, with daily tips and expert ideas.

Figure 1. A screenshot from the Learning area [56]

The goal of the Community area is to use the strength of virtual communities to provide real-life insights aimed at improving living habits. The Community area is organized around different zones (Figure 2) in which users discuss and share experiences among themselves with or without the supervision of an expert (physician, psychologist, nutritionist, etc).

Figure 2. A screenshot from the Community area

In the Learning and Community areas, users enjoy support and guidance, learn how to make wise choices and live healthily, and benefit from the exchange of practical experiences and tips from other users.

The goal of the Experience area is to use the feeling of presence provided by the virtual experience to practise both emotional and relational management and general decision-making and problem-solving skills. This area includes different zones (Figure 3) presenting critical situations related to the maintenance and relapse mechanisms (Mall, Supermarket, Pub, Restaurant, Kitchen, etc). Each of these environments is experienced only under supervision.

Figure 3. A screenshot from the Experience area (In particular, the kitchen has been created for people affected by food craving.)

In all three of these areas, the user is helped to develop specific strategies for avoiding and/or coping with their problems. After the experience, the coach explores the patient's understanding of what happened in the virtual experience and the specific reactions—emotional and behavioral—to the different situations experienced. If needed, some new strategies for coping with the situations are presented and discussed. In all three areas, type and intensity of care will vary depending on the type of intervention (eg, prevention vs treatment).

In our vision, Eureka could be an interesting starting point to test the efficacy of online virtual worlds in the prevention and treatment of different psychological disorders.

Conclusions

This paper addresses a broad and emerging idea in the field of eHealth: the use of 3-D virtual worlds for online mental health applications. As we have recently discussed elsewhere [57], 3-D online worlds have become not only fertile ground for psychologists exploring human behavior [58], but they are also starting to play an emergent role in health services. Why should this be so? Compared with traditional telehealth systems (videoconferencing, email, telephone, Web 1.0 applications, etc) and other available technologies (eg, CD or DVD), 3-D virtual worlds provide users with a more immersive and socially interactive experience, as well as a feeling of embodiment that has the potential to facilitate the clinical communication process and to positively influence group interaction and cohesiveness in group-based therapies. Moreover, unlike the available VR software (see, for example, NeuroVR [59]), 3-D virtual worlds, being Internet-based applications, can be used by different people from different places without physical limitations.

Although this new medium has the potential to improve existing eHealth applications, there are several challenges that need to be addressed. First, more basic psychological research is needed in order to gain a clearer understanding of psychological, communicative, and interpersonal aspects of avatar-based interactions and of the differences between this and other interaction modes. Second, to date, there is scant encouraging data coming from traditional telepsychology applications [60-63] and online communities [39,44] and no experimental or controlled data about the therapeutic effectiveness of online virtual worlds in patients with mental health disorders. Third, 3-D virtual worlds were not created with clinical purposes in mind. This means that clinicians and researchers have to create specific and protected environments to meet their clinical needs as well as the needs of patients. Further, as for any kind of eHealth system, it is important to define international guidelines for the development of 3-D virtual world–based clinical applications in order to reduce the risk of abuse and to guarantee appropriate levels of privacy. Finally, online virtual worlds have open access, meaning that it may be difficult to create safe therapeutic environments in which patients can interact with therapists without external interferences and with privacy protection. Also, cost issues should not be overlooked. The vast majority of virtual worlds have high subscription costs, which may be too expensive for private therapists; in February 2008, the price for an island in Second Life was US $1675 plus a US $295 monthly fee. Finally, most online worlds provide users with building tools (editors) that are not easy to use for nonexperts as they often require the user to learn script-based programming languages.

In conclusion, despite technical, ethical, and economic issues, we suggest that 3-D virtual worlds, used as an adjunct to face-to-face settings, may represent a valid opportunity for the future developments in eHealth. Our hope is that the present paper will stimulate a discussion within the research community

about the potential, the limitations, and the risks that this   emerging medium offers for cybertherapy applications.

Conflicts of Interest

None declared.

References

1. Graham P. Web 2.0. 2005. URL: http://www.paulgraham.com/web20.html [accessed 2008 Jul 25] [WebCite Cache ID 5VzpkrigE]
2. Eysenbach G. Medicine 2.0: social networking, collaboration, participation, apomediation, and openness. J Med Internet Res 2008;10(3):e22 (forthcoming). [doi: 10.2196/jmir.1030]
3. Kamel Boulos MN, Wheeler S. The emerging Web 2.0 social software: an enabling suite of sociable technologies in health and health care education. Health Info Libr J 2007 Mar;24(1):2-23. [Medline: 17331140] [doi: 10.1111/j.1471-1842.2007.00701.x]
4. Second Life. URL: http://secondlife.com/ [accessed 2008 Jul 25] [WebCite Cache ID 5VzqNH3yL]
5. There. URL: http://www.there.com/ [accessed 2008 Jul 25] [WebCite Cache ID 5Vzqxg401]
6. Active Worlds. URL: http://www.activeworlds.com/ [accessed 2008 Jul 25] [WebCite Cache ID 5Vzr9TKi3]
7. Second Life - Nutrition Game. URL: http://slurl.com/secondlife/ohio%25university/161/175/25/
8. ; Vital Lab. Second Life Development Service from the VITAL Lab @ Ohio University. Vital Wiki. URL: http://vital.cs.ohiou.edu/vitalwiki/index.php/Second_Life_%05%05Development [accessed 2008 Jul 25] [WebCite Cache ID 5VzreV6M1]
9. Kemp J. Second Life Heart Murmur Sim video demonstration. 2006. YouTube. URL: http://it.youtube.com/watch?v=xJY2Iwbzop4 [accessed 2008 Jul 25] [WebCite Cache ID 5Vzs3C2LJ]
10. Second Life - Heart Murmur Sim. URL: http://slurl.com/secondlife/waterhead/124/56/32/
11. Second Life - Virtual Hallucinations (UC Davis). URL: http://slurl.com/secondlife/sedig/26/45/21/
12. Yellowlees PM, Cook JN. Education about hallucinations using an internet virtual reality system: a qualitative survey. Acad Psychiatry 2006;30(6):534-539 [FREE Full text] [Medline: 17139026] [doi: 10.1176/appi.ap.30.6.534]
13. Second Life - The Gene Pool in Second Life. URL: http://slurl.com/secondlife/genome/137/87/29
14. Second Life - VNEC—Virtual Neurological Education Centre in Second Life. URL: http://slurl.com/secondlife/Lost%20Islands%20NW/48/83/22
15. Second Life - Healthinfo Island. URL: http://slurl.com/secondlife/Healthinfo%20Island/184/61/22
16. Boulos MNK, Hetherington L, Wheeler S. Second Life: an overview of the potential of 3-D virtual worlds in medical and health education. Health Info Libr J 2007 Dec;24(4):233-245. [Medline: 18005298] [doi: 10.1111/j.1471-1842.2007.00733.x]
17. van Kokswijk J. Hum@n, Telecoms & Internet as Interface to Interreality. Hoogwoud, The Netherlands: Bergboek; 2003.
18. Lee KM. Why presence occurs: evolutionary psychology, media equation, and presence. Presence 2004;13(4):494-505. [doi: 10.1162/1054746041944830]
19. Riva G. Virtual reality and telepresence. Science 2007 Nov 23;318(5854):1240-1242. [Medline: 18033867] [doi: 10.1126/science.318.5854.1240d]
20. Riva G, Anguera MT, Wiederhold BK, Mantovani F. From Communication to Presence: Cognition, Emotions and Culture towards the Ultimate Communicative Experience. Amsterdam, The Netherlands: IOS Press; 2006.
21. Zhao S. Toward a taxonomy of copresence. Presence 2003;12(5):445-455. [doi: 10.1162/105474603322761261]
22. Biocca F, Harms C, Burgoon J. Toward a more robust theory and measure of social presence: review and suggested criteria. Presence 2003;12(5):456-480. [doi: 10.1162/105474603322761270]
23. Reeves B. "Being there": Television as Symbolic versus Natural Experience. Stanford, CA: Institute for Communication Research, Stanford University; 1991.
24. Casanueva JS, Blake EH. The Effects of Avatars on Co-presence in a Collaborative Virtual Environment. Technical Report CS01-02-00 TR. Cape Town, South Africa: Department of Computer Science, University of Cape Town; 2001.
25. Schroeder R. The Social Life of Avatars. New York: Springer; 2002.
26. Bente G, Rüggenberg S, Krämer NC. Social presence and interpersonal trust in avatar-based, collaborative net-communications. In: 7th Annual International Workshop on Presence 2004. Valencia, Spain: Editorial Universidad Politécnica de Valencia; 2004.

XSL·FO
RenderX

27. Bente G, Rüggenberg S, Krämer NC. Virtual encounters. Creating social presence in net-based collaborations. In: Slater M, editor. 8th Annual International Workshop on Presence. London, UK: University College London; 2005:97-102.

28. Fabri M, Moore DJ, Hobbs DJ. The emotional avatar: nonverbal communication between inhabitants of collaborative virtual environments. In: Braffort A, editor. Gesture-Based Communication in Human-Computer Interaction: Springer Lecture Notes in Artificial Intelligence 1739. New York: Springer; 1999:245-248.

29. Yee N, Bailenson JN, Urbanek M, Chang F, Merget D. The unbearable likeness of being digital: the persistence of nonverbal social norms in online virtual environments. Cyberpsychol Behav 2007 Feb;10(1):115-121. [Medline: 17305457] [doi: 10.1089/cpb.2006.9984]

30. Gorini A, Riva G. Virtual reality in anxiety disorders: the past and the future. Expert Rev Neurother 2008 Feb;8(2):215-233. [Medline: 18271709] [doi: 10.1586/14737175.8.2.215]

31. Riva G, Gaggioli A, Villani D, Preziosa A, Morganti F, Corsi R, et al. NeuroVR: an open source virtual reality platform for clinical psychology and behavioral neurosciences. Stud Health Technol Inform 2007;125:394-399. [Medline: 17377310]

32. Pull CB. Current status of virtual reality exposure therapy in anxiety disorders: editorial review. Curr Opin Psychiatry 2005 Jan;18(1):7-14. [Medline: 16639177]

33. Allison SE, von Wahlde L, Shockley T, Gabbard GO. The development of the self in the era of the internet and role-playing fantasy games. Am J Psychiatry 2006 Mar;163(3):381-385 [FREE Full text] [Medline: 16513856] [doi: 10.1176/appi.ajp.163.3.381]

34. Rizzo A, Pair J, McNerney PJ, Eastlund E, Manson B, Gratch J, et al. Development of a VR therapy application for Iraq war military personnel with PTSD. Stud Health Technol Inform 2005;111:407-413. [Medline: 15718769]

35. Wiederhold BK, Wiederhold MD. Virtual Reality Therapy for Anxiety Disorders. Washington, DC: American Psychological Association Press; 2004.

36. Winkelman WJ, Choo CW. Provider-sponsored virtual communities for chronic patients: improving health outcomes through organizational patient-centred knowledge management. Health Expect 2003 Dec;6(4):352-358. [Medline: 15040797] [doi: 10.1046/j.1369-7625.2003.00237.x]

37. Wenger E. Communities of Practice: Learning, Meaning, and Identity. Cambridge, UK: Cambridge University Press; 1998:318.

38. Fildes J. Virtual world 'tackles paranoia.'. BBC. 2003. URL: http://news.bbc.co.uk/2/hi/health/3251365.stm [accessed 2008 Jul 25] [WebCite Cache ID 5VztrlCVU]

39. Fildes J. Virtual treatment for US troops. BBC. 2007. URL: http://news.bbc.co.uk/2/hi/science/nature/6375097.stm [accessed 2008 Jul 25] [WebCite Cache ID 5VztcArDh]

40. Lester J. About Brigadoon. Brigadoon: An Innovative Online Community for People Dealing with Asperger's Syndrome and Autism. Braintalk Blog. URL: http://braintalk.blogs.com/brigadoon/2005/01/about_brigadoon.html [accessed 2008 Jul 25] [WebCite Cache ID 5ZdXqHvIx]

41. Biever C. Web removes social barriers for those with autism. 2007. New Scientist. URL: http://technology.newscientist.com/channel/tech/mg19426106.100-web-removes-social-barriers-for-those-with-autism.html [accessed 2008 Jul 25] [WebCite Cache ID 5VzuV4H7B]

42. Brady J. How 'Second Life' therapy helps Asperger's patients. 2008. WFAA TV News. URL: http://www.wfaa.com/sharedcontent/dws/wfaa/localnews/news8/stories/wfaa080111_lj_brady.11fb5bac.html [accessed 2008 Jul 25] [WebCite Cache ID 5Vzu9DCSQ]

43. Second Life - Autistic Liberation Front in Second Life. URL: http://slurl.com/secondlife/Porcupine/29/177/113

44. Second Life - Live2give. URL: http://slurl.com/secondlife/144/210/28

45. Lester J. All about Live2Give. Live2Give: An innovative Online Community for people dealing with Cerebral Palsy and similar conditions. Braintalk Blog. URL: http://braintalk.blogs.com/live2give/2005/01/all_about_live2.html [accessed 2008 Jul 25] [WebCite Cache ID 5ZdXuH9Wf]

46. Terdiman D. Second Life Teaches Life Lessons. Second Life Herald. 2005. URL: http://www.secondlifeherald.com/slh/2007/02/interview [accessed 2008 Apr 10] [WebCite Cache ID 5VzvNQHyR]

47. Aquacade A. Interview With the Agoraphobic: Fighting the Fear in Second Life. Second Life Herald. 2007. URL: http://www.secondlifeherald.com/slh/2007/02/interview_with__1.html [accessed 2008 Aug 2] [WebCite Cache ID 5ZnYhV7wV]

48. Second Life - Agoraphobia Support Headquarters. URL: http://slurl.com/secondlife/Neptune/128/110/30

49. Luo JS. Virtual reality therapy: on your desktop today. Primary Psychiatry 2007;14:20-22.

50. Glueckauf RL, Pickett TC, Ketterson TU, Loomis JS, Rozensky RH. Preparation for the delivery of telehealth services: a self-study framework for expansion of practice. Prof Psychol: Res Pract 2003;34(2):159-163. [doi: 10.1037/0735-7028.34.2.159]

51. Koocher GP, Morray E. Regulation of telepsychology: a survey of state attorneys general. Prof Psychol: Res Pract 2000;31(5):503-508. [doi: 10.1037/0735-7028.31.5.503]

52. Jerome LW, DeLeon PH, James LC, Folen R, Earles J, Gedney JJ. The coming of age of telecommunications in psychological research and practice. Am Psychol 2000 Apr;55(4):407-421. [Medline: 10812693] [doi: 10.1037/0003-066X.55.4.407]

53. American PAEC. Services by Telephone, Teleconferencing, and lnternet. Washington, DC: APA; 1997.

XSL·FO
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54.   ; American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. Fourth Edition (Text Revision). Washington, DC: APA; 2000.

55.   O'Donohue W, Ferguson KE. Evidence-based practice in psychology and behavior analysis. Behav Analyst Today 2006;7:335-350.

56.   Second Life - Eureka. URL: http://slurl.com/secondlife/eureka/203/113/29

57.   Gorini A, Gaggioli A, Riva G. Virtual worlds, real healing. Science 2007 Dec 7;318(5856):1549. [Medline: 18063769] [doi: 10.1126/science.318.5856.1549b]

58.   Miller G. Living in societies. The promise of parallel universes. Science 2007 Sep 7;317(5843):1341-1343. [Medline: 17823341] [doi: 10.1126/science.317.5843.1341]

59.   NeuroVR. URL: http://www.neurovr.org/ [accessed 2008 Jul 25] [WebCite Cache ID 5VzvaCHeA]

60.   Alcañiz M, Botella C, Baños R, Perpiñá C, Rey B, Lozano JA, et al. Internet-based telehealth system for the treatment of agoraphobia. Cyberpsychol Behav 2003 Aug;6(4):355-358. [Medline: 14511446] [doi: 10.1089/109493103322278727]

61.   Goldfield GS, Boachie A. Delivery of family therapy in the treatment of anorexia nervosa using telehealth. Telemed J E Health 2003;9(1):111-114. [Medline: 12699614] [doi: 10.1089/153056203763317729]

62.   Miller TW, Kraus RF, Kaak O, Sprang R, Burton D. Telemedicine: a child psychiatry case report. Telemed J E Health 2002;8(1):139-141. [Medline: 12020414] [doi: 10.1089/15305620252933482]

63.   Nelson EL, Barnard M, Cain S. Treating childhood depression over videoconferencing. Telemed J E Health 2003;9(1):49-55. [Medline: 12699607] [doi: 10.1089/153056203763317648]

Abbreviations

3-D: three dimensional
IPD: interpersonal distance
PDA: personal digital assistant
VR: virtual reality

Original Paper

Social Uses of Personal Health Information Within PatientsLikeMe, an Online Patient Community: What Can Happen When Patients Have Access to One Another's Data

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Abstract

Background: This project investigates the ways in which patients respond to the shared use of what is often considered private information: personal health data. There is a growing demand for patient access to personal health records. The predominant model for this record is a repository of all clinically relevant health information kept securely and viewed privately by patients and their health care providers. While this type of record does seem to have beneficial effects for the patient–physician relationship, the complexity and novelty of these data coupled with the lack of research in this area means the utility of personal health information for the primary stakeholders—the patients—is not well documented or understood.

Objective: PatientsLikeMe is an online community built to support information exchange between patients. The site provides customized disease-specific outcome and visualization tools to help patients understand and share information about their condition. We begin this paper by describing the components and design of the online community. We then identify and analyze how users of this platform reference personal health information within patient-to-patient dialogues.

Methods: Patients diagnosed with amyotrophic lateral sclerosis (ALS) post data on their current treatments, symptoms, and outcomes. These data are displayed graphically within personal health profiles and are reflected in composite community-level symptom and treatment reports. Users review and discuss these data within the Forum, private messaging, and comments posted on each other's profiles. We analyzed member communications that referenced individual-level personal health data to determine how patient peers use personal health information within patient-to-patient exchanges.

Results: Qualitative analysis of a sample of 123 comments (about 2% of the total) posted within the community revealed a variety of commenting and questioning behaviors by patient members. Members referenced data to locate others with particular experiences to answer specific health-related questions, to proffer personally acquired disease-management knowledge to those most likely to benefit from it, and to foster and solidify relationships based on shared concerns.

Conclusions: Few studies examine the use of personal health information by patients themselves. This project suggests how patients who choose to explicitly share health data within a community may benefit from the process, helping them engage in dialogues that may inform disease self-management. We recommend that future designs make each patient's health information as clear as possible, automate matching of people with similar conditions and using similar treatments, and integrate data into online platforms for health conversations.

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Introduction

This project investigates how patients react to the shared use of what is often considered private information: personal health data. Encouraged by technological trends and policies promoting patients' rights, there is a mounting demand for flexible access to personal health information [1]. While personal health information systems vary, the predominant model is that of a central repository for *all* health information generated within clinical contexts (eg, health history, diagnoses, allergies, current treatments) that is kept securely for view only by patients and their health care providers [2].

While research in this area is still sparse, this type of record does seem to have beneficial effects for the patient–physician relationship. Provider-supplied personal health records have been shown to improve the communication and trust between the patients and health care providers [1,3] and the completeness of patient-reported data and the quality of the clinical encounter [4]. Still, the utility of a personal health information system for the primary stakeholders themselves—the patients—is not well documented or understood. One risk is that a collection of static medical information may be overly complex for the patient and therefore overwhelming. The prospect of correctly interpreting a large corpus of statically presented electronic health records causes concern even for some physicians [5]. As a result, a medical informatics working group asserted that the ideal personal health record is more than just a static repository for patient data; it should combine data, knowledge, and software tools to help patients become active participants in their own care [6].

This paper reports on a health information system, PatientsLikeMe, designed specifically for patients to use themselves and in cooperation with other patients with the same disease. In this system, patients report their relevant health information, which is presented as coherent graphical displays on their profile. Member profiles are posted where other members can have access to them, providing a basis for passive information sharing and active dialogue among patients.

This system is based on two assumptions. First, that given appropriate tools, patients will be able to interpret and learn from visual displays of personal health data [7]. This assumption is built on work on "imagery as data" in health care, suggesting that, through collecting, analyzing, and explaining visual data for themselves, patients can gauge the impact of daily behavior on health outcomes [8,9]. Second, sharing personal health data and collaboratively reviewing and critiquing it will enhance utility of the data for each contributor. Research has shown that peer-led communities that do not use personal data have documented benefits for patient knowledge, discussion, and health care utilization: users not only provide one another with support, they teach each other the science and medical information they need to understand their disease [10] and empower one another to seek out physicians who will recognize and treat their illness [11]. Communities have been shown to support reciprocal information sharing and help move participants from information gathering to positive behavioral change [12] and to provide a venue for patients to discuss

morality and medical ethics [13]. Few studies isolate the effect of peer-to-peer communities on health outcomes [14]. Outside of the health domain, one quality of social Web, or Web 2.0, applications is that the applications gain value through their use [15]. Web 2.0 communities compile resources and create shared knowledge that is beyond the scope of a single individual. Framing online patient interaction around displays of personal health information can create a Web 2.0 community that may enrich patient conversations around health practice.

In this work we focus on patients who have an incurable and relatively rare life-altering disease. We do so because these patients may benefit more than other patients from a personal health record [1,2] and because their mobility constraints complicate face-to-face meetings. The platform was conceptualized for a broad set of conditions and was first implemented for amyotrophic lateral sclerosis (ALS), also called motor neuron disease or Lou Gehrig's disease. ALS is a rare and fatal neurodegenerative disease that begins with loss of voluntary motor function and progresses to the inability to communicate, swallow, and breathe unaided. There is no cure for ALS, but there is one FDA-approved drug for its treatment, rilozule (Rilutek), which marginally lengthens life [16]. Patients use other methods to manage some of the symptoms (eg, fluoxetine [Prozac], an antidepressant, to help reduce excessive saliva) and assistive technologies to take over when biological systems fail. ALS patients and their caregivers have to decide when and if to use end-of-life interventions such as a feeding tube or ventilator.

The PatientsLikeMe platform is being continuously reviewed to understand how this model of data sharing impacts patient participation in medical decisions and organization of daily self-care practices. The primary question of the current study was how patients explicitly utilize visual displays of health information to communicate with specific patients about their treatments and disease experience. We also sought to describe the kind of dialogues that emerge when individual health information is made available within a patient community. To successfully engage in these discussions implies both the ability to draw useful conclusions from data and a level of comfort with sharing, what is often considered, personal information. We sought to answer this question by compiling and analyzing the kinds of questions, comments, and discussions that relate directly to shared, personal medical information.

Methods

This was a design-based qualitative research study [17,18] to examine how users of the online PatientsLikeMe ALS community refer to data in discussions with specific peers. In this preliminary study, we only focus on how users employ elements of another user's personal health profile in a discussion with that user.

The Platform

The PatientsLikeMe ALS community was opened to the public in March 2006. Patients join the site based on the recommendation of their health providers, other patients, or patient blogs or after finding the site through online searches

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and Google "ad words." A year and a half after launch, the community contained 1570 verified patients, about 1140 living in the United States. These members represent almost 4% of the estimated ALS cases in the United States [19].

Personal Health Profiles and Data

On PatientsLikeMe, each patient enters a combination of structured and unstructured data, which are compiled and presented as a profile of his or her health history and shared within the site. Profiles contain a summary representation of the patient's current status: a diagram that maps functional impairment to areas of the body (Figure 1), a personal picture, an autobiographical statement, a diagnosis history, and a series of charts. The "nugget" summary diagram displays the current function score as a color code mapped onto affected areas of the body as well as the number of years with the disease, an iconic representation of the equipment currently used, and stars indicating level of participation on the site (see Figure 1). As in similar projects [20-22], PatientsLikeMe created a graphical display of health information as an alternative to static lists and tables in order to make the data more accessible. The primary chart on the ALS site is a line graph of the individual's functional level over time, superimposed onto a backdrop of population-level data (Figure 2). Function is assessed through an adaptation of the clinically validated, self-administered form of the revised ALS functional rating scale (ALSFRS-R) [23].

Figure 1. Individual summary information (the "nugget")

Figure 2. Charts comprising the personal profile

Below the functional rating scale (FRS) chart are modified Gantt charts representing all the treatments taken and symptoms experienced by the patient. Although each user is asked about a core set of common symptoms, both treatments and additional symptoms are built with a flexible architecture such that patients define and extend the underlying ontology. In other systems, Gantt charts used to depict patient information facilitated faster comparisons between data types and improved the recall of medical information in comparison to tabular data [24]. The patient can rearrange charts within the profile to explore relationships between data types. The profile is available for personal use and to be browsed and critiqued by other users of the site.

Aggregate Resources

Data are also aggregated from all individuals in the community to create community summaries of treatments and symptoms. Treatment reports contain standard descriptions of the treatment and display community-level data (eg, distribution of dosage levels, time on the treatment, reasons individuals have started and stopped the treatment) and relevant content culled from the Forum on users' impressions of the treatment. Symptom reports show analogous information: the prevalence and severity in the community of each symptom and the treatments people are taking for each one. Each element in these reports is hyperlinked to related items of interest, for example, to other people taking the treatment for the same reason or in the same amount or to Forum posts on that topic.

Social Tools

Using search and browsing tools, members can locate other patients in similar circumstances and with shared medical experiences. Members discuss the profiles and reports as well as general health concerns through the Forum, private messages, and comments they post on one another's profiles. The Forum is a threaded dialogue available to every member of the community to pose questions, research findings, share coping strategies, and so forth. Private messages are emails sent from one user to another within the site; they are not read by other users or site administrators. Comments are remarks that one user posts on another's profile, which are viewable by anyone in the community. Users can delete comments from their own profile. Each contribution made using any of these functions is labeled with a graphic representation (the nugget) giving a snapshot view of the contributor's history and health status; the nugget is also linked to the user's complete profile.

Data Selection

On the site, there are five main categories of personal health data reported within each profile: the "about me" section (demographics, place of residence, and disease history data), a free-form biographical essay, functional ratings, treatments, and symptoms. Users interact with one another in three ways: the Forum, private messages, and comments posted to patient profiles.

For the present inquiry, we were interested in user remarks that refer to another's individual-level personal health data. On the site, these data are displayed in the personal profile. We excluded forum posts, which are not designed to connect

discussion and data of another specific user's experience. Private messages were not analyzed because we do not access or read the content of private messages sent within the site. The analysis focused on the comments left on personal profiles. These are of prime interest in this analysis for two reasons. First, their proximity, posted at the end of the profile, may lead users to reference profile data within their comments. Second, their accessibility to all users defines them as part of the site available for research purposes.

Sampling

Over the history of the site (December 2006 to February 2008), users in the ALS community generated a total of 17,059 comments affixed to another user's profile. More than half of these included a predefined message—"Thank you for filling out your profile!"—that can be created with a single click, edited, and then sent. To date, 7852 user-created comments have been composed from scratch, so we focused on these original messages in the analysis. A total of 63% (986/1570) of the patients in the study period posted at least one original comment on the site. To identify comments that explicitly referenced profile data, we used a strategic sampling procedure. In a preliminary analysis of 500 original comments, we identified phrases that commonly co-occurred with references to profile data. These phrases were "I see you," "I can see you," and "notice you." Approximately 30% of the 500 comments contained these phrases. No other pattern could be identified to characterize the remaining comments. An automated search of the full set of 7852 comments identified all postings that contained any of the specified phrases and added these comments to a database table for manual analysis, along with the relevant demographic data and whether these comments resulted in a response. Privacy concerns were addressed by not collecting identifying information and changing the demographic data for published segments. Using a grounded theory approach [25], a set of codes was developed. Using this set of codes, each comment was independently coded by each of the authors, differences were reconciled, and then themes were identified and discussed by both authors. To better understand how these comments fit into larger dialogues, we documented whether the comments initiated the exchange and if the commenter received responses in the form of either a private message or a comment. We tallied the number of comment and private message responses (without looking at the message contents).

Results

We identified 123 postings by 95 users that met the criteria based on the key phrases. Among these comments, more referred to treatments (29/123, 23%) than to symptoms or outcomes (9/123, 7%). Almost half of the comments (56/123, 45.5%) included at least one question, and half of these questions were explicit requests for advice (34/123, 28%).

The following are typical examples of comments in three major categories: (1) targeted questions to others with relevant experience, (2) advice and recommendations, and (3) forming and solidifying relationships based on similarity. We also estimated how many of these comments led to ongoing discussion among users. Names of users have been changed.

Targeted Questions to Others With a Shared Experience

When considering a new treatment, one user observed what another member was using and stated:

> *I notice you are using ginger root and you believe it is slowing your progression. I'm very interested in this. Can you tell me more about how it's working for you?*

Another user, also curious about a nutraceutical, conducted a more complete inquiry. He sent almost identical versions of an in-depth request for information rather than addressing a specific comment to each individual on the treatment:

> *I see you are using Glyconutrients. What are the exact ones that you're using, how long have you been using them for, and what benefits if any have you seen. I have heard a lot of encouraging things about them, but I have yet to hear anything about their use by ALS patients. Are they helping with a particular symptom? Please let me know what you have learned by taking these supplements. Blessings to you and your family.*

In such comments, users with a particular treatment question often addressed their question to other members already using that treatment. For the above two cases, the questions were about nutraceuticals and their perceived efficacy. In other comments, users asked about prescription pharmaceuticals, dosage levels, or experience using a piece of equipment. In all of these scenarios, one user with a question apparently identified another user with relevant experience and then asked about his or her perception of the treatment's efficacy.

The graphic depiction of the length of time on a treatment (in the Gantt charts) pointed one user to identify another as an appropriate recipient for his question. Since this man was considering a feeding tube, he asked a woman on the site about her experience:

> *[Jen], I'm a new member of PLM like yourself. I notice you have had a tube for about 8 months. I'm having difficulty eating, so the neurologist suggested*

> *I look into getting one. My meeting with the gastroenterologist did not leave me with desire to get one. It would help me if you would send me a message about your experience, pro and con, with your feeding tube.* [Peter]

In this case, Peter explicitly referenced the amount of time Jen had been using an assistive technology as evidence of her value as an advisor. Although he had consulted with health care providers, he sought out another patient's opinion with the implication that it would contribute to his own decision.

In the above cases, users identified a single feature of a profile then asked an appropriate question. Other users made more sophisticated observations based on multiple charts and data types. For example, Adam, an ALS patient considering the use of a breathing assistance device—bilevel positive airway pressure (BiPAP)—asked the following:

> *Hi [D] I am [Adam] in the PLM web site. My als was like yours breathing onset. I see your FRS improved a bit after you went onto BIPAP in april 06. Did it in fact make that much difference.??* [Adam]

To ask this question, Adam apparently cross-referenced two charts in the profile to see the relationship between beginning to use various interventions, including a BiPAP, which is displayed in one type of chart, and experiencing improved function, which is displayed in another. In this case, the relationship looked clear (Figure 3). In fact, the displayed clarity of the relationship appeared to give Adam pause since he asked for confirmation.

In the preceding examples, users with a specific question identified another member and addressed their question to him or her. The criterion leading to that identification appears to be simply taking the medication or using the treatment. In one case, a user referenced the amount of time a member had been using a technology as a factor in identifying an individual as a credible resource. Using other members as a resource to inform treatment decisions emerged as a reoccurring use of comments within the site (29/123, 24%).

Figure 3. Patient profile of PatientsLikeMe member "D" (with added explanatory remark "Based on the charts..", which is not part of the original screenshot)
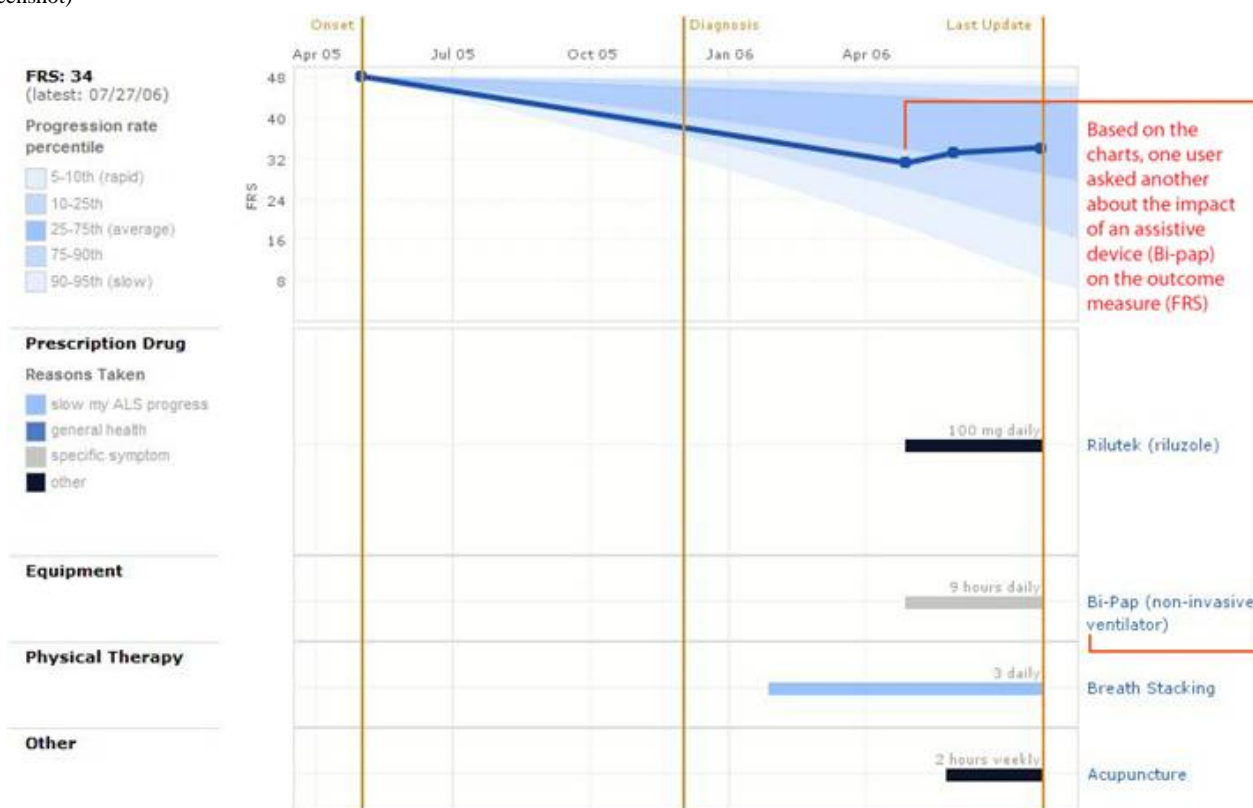
Advice and Recommendations

Browsing the site, users frequently posted their remarks on one another's profiles, in some cases sharing their own relevant experience. One man observed another's symptom:

> I see you note emotional lability. I had that very bad, but now I take a compound of dextromethorphan and quinidine that controls it beautifully.

In this case, a user offered personally acquired knowledge to another member listing a shared symptom (depicted within a modified Gantt chart). This was not an isolated instance: in five of the comments users provided similar recommendations specifically around observed symptoms, including bed sores and cramping. In each case, the comment offered advice based on a positive personal experience and included a treatment recommendation and a method for administering that treatment.

Users' advice went beyond sharing personal treatment and symptom experiences. Within the "about me" section of the profile, many users provided their city and state of residence. Some members reading the profile referenced this information to make geographically appropriate suggestions. For example, one patient wrote to a caregiver on the site about a local support group:

> Hi [Bill]. ... There will be another ALS support group starting up next Tuesday Feb.20th in Holt. Just checking to see if your parents were interested...

In similar references to location, four users either mentioned or explicitly invited others to support groups.

In one case, a user noted the individual's region and type of onset to suggest a research study on a new technology designed to address her specific situation:

> [Joanne], I see you are legs onset; have you heard about the new diaphragm implants they are doing at Case-Western and Johns Hopkins? It means you don't have to vent to breathe. [George]

George had a piece of information about a location- and topic-specific resource available to patients. He referenced Joanne's diagnosis history (onset type) to make a recommendation. Using posted data, he was able to connect the individual to the resource.

In these cases, users offered advice and recommendations to others. In most cases, these recommendations stemmed from personal experience with taking a drug or using a device, but they also stemmed from personal research, as in the last example where a member offered knowledge of a research study to another user. In other online applications, individuals may share personal experience through messages broadcasted to a large audience. In this context, users delivered targeted messages to particular users they think may benefit from them.

Forming and Solidifying Relationships Based on Similarity

Comments also function as a mechanism for creating and maintaining relationships, particularly around points of similarity: 25% (31/123) of the comments we analyzed identified a shared attribute, hobby, or concern within a broader comment or question. Locating a similar patient, one member quoted what

they had in common medically as a basis to invite further contact:

> *Hi [Michael], I see we are pretty similar. I am 62 dx 11/06 with leg onset. I need a walker to help me walk. I move slower and have had a few recent falls due to my leg dragging. I would like to be available if you want to compare progress. I started noticing symptoms a year ago, but just dx this month.*

Referencing diagnosis history, this user made a connection with another member in the community. For patients in unusual situations, the site allows for finding a similar individual even when there are only a few. In the following case, another user expressed her pleasure in finding others with a shared but atypical disease progression:

> *hi [Rachel]. yes same boat indeed. i am so glad to find this site because i see there are many of us with slower progression than stereotypical. the support groups locally really focus of immediate need patients and us long timers are not so immediate except we still have concerns and fears, etc so it has been so great to see how long timers cope with losing our function slowly and wondering which part is going to fail next. hers my personal email; … id love to talk more.*

In these cases, the first patient had explicitly invited further contact, and the second suggested a willingness to share data even beyond the anonymous structure of the site by giving her personal email address.

In addition, there were examples of patients seeking out others based on non-medical criteria: 18 of the 31 comments on similarity were based on non-medical criteria including location, employment history, astrological sign, and shared interests. As with the medically based examples, the site facilitated meeting of people with shared concerns—people who probably would not have met offline.

Initiating Ongoing Discussion

All 123 comments were analyzed as single units, but the reality is that comments may occur within ongoing exchanges. Without looking at the contents of private messages, we examined the full exchange of comments and messages between the sender and the recipient of all the comments studied. We found that these comments served to both continue an exchange between the two users (59/123, 48%) and initiate new exchanges (64/123, 52%). In the initiate cases, 56% (36/64) of the comments received at least one reply. In more than half the replies (20/36, 55%), the recipient continued the exchange in the "public" sphere of the site either through comments only (12/36, 33%) or through a combination of private messages and comments (8/36, 22%). On the other hand, among the cases where a comment emerged in an ongoing exchange, 57 of 59 comments were responded to, with comments being used in 68% of the exchanges.

Discussion

While there is growing demand by patients for access to their own health data, there is little information on how other people will use these data if they are made available to others with similar medical concerns. For this study, we made use of a platform designed to help patients share personal health information by representing key data in a standardized graphical format within accessible personal profiles. By looking at one of the social behaviors within this platform—comments that explicitly reference other users' health data—we begin to get a sense of how patients employ this information.

This analysis identifies and analyzes a small but illustrative subset of all user-generated comments—those in which members explicitly refer to another's data, indicating that they have examined and interpreted posted medical information. We see cases where such data serve as a focal point for detailed discussions of health-related topics such as treatment decisions and symptom control. We identify three themes in the comments studied: asking advice of a user with a particular experience, offering advice to a user with a specific symptom or health problem, and fostering relationships based on shared attributes. In other situations, research has shown that perceived similarity to self in attributes and attitudes predicts positive social evaluations [26,27]; in these comments on PatientsLikeMe, similarity appears to operate analogously, heightening interest in another user. Unlike in other domains, this type of similarity—based specifically on shared medical characteristics—may contribute to positive medical outcomes as others in similar situations may be able to offer pertinent advice and suggestions and logistic as well as social support. Although small in number, the comments selected for this study represent an undetermined fraction of all uses of profile data. Nevertheless, they offer insight into the potential value of patients sharing health information.

This study represents a first examination of the use of shared medical information, which is still a novel model for personal health data. It is limited in scope by several factors, including the functionality studied and the sampling method employed. In this study, we focused deliberately on posted comments and then only on those that fit a predefined search criterion for identifying comments likely to explicitly reference another user's health data. Our sample is only a small percentage of the total number of elements on the multidimensional site. As a result, we do not know what an analysis of all the references to data on the site would reveal. For example, data may function to define the history of a patient, which in turn enhances the forum conversation; viewing another's profile may reduce a sense of isolation that could result from living with a disease; and other profiles may help individuals contextualize their own experience within a community of fellow patients. Future research based on interviews and surveys could investigate these possibilities more thoroughly. We also need to understand why the comments that passed our screen for prima facie use of data are only a small percentage of the total comments generated on the site. Perhaps the rule we employed to select our sample—only including comments containing particular word strings—did not capture all relevant comments. As a result, this

may have been a convenient rather than complete sampling of those comments. Another possible reason for the limited number of data-centered comments is that discussing profile data is only one of the many uses members make of each other's posted medical information, with one such use, posting prescribed comments, being actively encouraged by the site design. A member, with one click, can post a prescribed comment to another member, thanking him or her for entering personal information. Although we found that about half of the comments did not include this prescribed comment and were written "from scratch," that design decision may influence how members use each other's profiles.

At the same time, the presence and apparent value of comments that explicitly reference data suggest the need for design innovations that promote data-centered patient conversation. The current design does so by offering the ability to search for other users based on criteria including treatments, symptoms, and demographics, as well as by providing both open commenting and private messaging. Future designs could include single-click functionality to ask another user about a shared experience, enhanced visualization techniques to facilitate the interpretation of the health profile, methods to search for people based on a larger variety of characteristics, and the ability to comment on a specific portion of someone's health profile. Our analysis also suggests that particular comments may be useful to a wider audience; therefore, a method of identifying, archiving, and presenting such comments for other individuals should be investigated.

Acknowledgments

Conflicts of Interest

References

1. Pagliari C, Detmer D, Singleton P. Potential of electronic personal health records. BMJ 2007 Aug 18;335(7615):330-333. [Medline: 17703042] [doi: 10.1136/bmj.39279.482963.AD]

2. ; Markle Foundation. Connecting for Health. Connecting Americans to Their Healthcare. Final Report. Working Group on Policies for Electronic Information Sharing Between Doctors and Patients. New York: Markle Foundation; 2004. URL: http://www.connectingforhealth.org/resources/wg_eis_final_report_0704.pdf [WebCite Cache ID 5OpjigDv9]

3. Tjora A, Tran T, Faxvaag A. Privacy vs usability: a qualitative exploration of patients' experiences with secure Internet communication with their general practitioner. J Med Internet Res 2005;7(2):e15 [FREE Full text] [Medline: 15998606] [doi: 10.2196/jmir.7.2.e15]

4. Kim EH, Wang M, Lau C, Kim Y. Application and evaluation of personal health information management system. Conf Proc IEEE Eng Med Biol Soc 2004;5:3159-3162. [Medline: 17270950] [doi: 10.1109/IEMBS.2004.1403891]

5. Robeznieks A. Getting personal. Legal liability, patient-data overload among issues making physicians uneasy over emergence of personal health records. Mod Healthc 2007 May 21;37(21):40-42. [Medline: 17824189]

6. Tang PC, Ash JS, Bates DW, Overhage JM, Sands DZ. Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption. J Am Med Inform Assoc 2006;13(2):121-126 [FREE Full text] [Medline: 16357345] [doi: 10.1197/jamia.M2025]

7. Beaudin JS, Intille SS, Morris ME. To track or not to track: user reactions to concepts in longitudinal health monitoring. J Med Internet Res 2006;8(4):e29 [FREE Full text] [Medline: 17236264] [doi: 10.2196/jmir.8.4.e29]

8. Smith BK, Reiser BJ. Explaining behavior through observational investigation and theory articulation. J Learn Sci 2005;14(3):315-360. [doi: 10.1207/s15327809jls1403_1]

9. Smith BK, Frost J, Albayrak M, Sudhakar R. Facilitating narrative medical discussions of type 1 diabetes with computer visualizations and photography. Patient Educ Couns 2006 Dec;64(1-3):313-321. [Medline: 16859870] [doi: 10.1016/j.pec.2006.03.011]

10. Hoch D, Ferguson T. What I've learned from E-patients. PLoS Med 2005 Aug;2(8):e206 [FREE Full text] [Medline: 16060721] [doi: 10.1371/journal.pmed.0020206]

11. Barker KK. Electronic support groups, patient-consumers, and medicalization: the case of contested illness. J Health Soc Behav 2008 Mar;49(1):20-36. [Medline: 104589882]

12. Bonniface L, Green L. Finding a new kind of knowledge on the HeartNET website. Health Info Libr J 2007 Dec;24 Suppl 1(s1):67-76. [Medline: 18005296] [doi: 10.1111/j.1471-1842.2007.00742.x]

13. Rier DA. Internet social support groups as moral agents: the ethical dynamics of HIV+ status disclosure. Sociol Health Illn 2007 Nov;29(7):1043-1058. [Medline: 18092982]

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14.   Eysenbach G, Powell J, Englesakis M, Rizo C, Stern A. Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. BMJ 2004 May 15;328(7449):1166 [FREE Full text] [Medline: 15142921] [doi: 10.1136/bmj.328.7449.1166]

15.   Musser J, O'Reilly T. Why Web 2.0 Matters and How You Can Make the Most of It: O'Reilly; 2006.

16.   Miller RG, Bouchard JP, Duquette P, Eisen A, Gelinas D, Harati Y, et al. Clinical trials of riluzole in patients with ALS. ALS/Riluzole Study Group-II. Neurology 1996 Oct;47(4 Suppl 2):S86-90; discussion S90-2. [Medline: 8858057]

17.   ; Design Based Research Collective. Design-based research: an emerging paradigm for educational inquiry. Educ Res 2003;32(1):3. [doi: 10.3102/0013189X032001003]

18.   Collins A, Joseph D, Bielaczyc K. Design research: theoretical and methodological issues. J Learn Sci 2004;13(1):15-42. [doi: 10.1207/s15327809jls1301_2]

19.   Who Gets ALS. ALS Association. URL: http://www.alsa.org/als/who.cfm [accessed 2008 Apr 25] [WebCite Cache ID 5Y0NuDIU9]

20.   Plaisant C, Milash B, Rose A, Widoff S, Shneiderman B. LifeLines: visualizing personal histories. In: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems: Common Ground. New York: ACM; 1996. [doi: 10.1145/238386.238493]

21.   Plaisant C, Heller D, Li J, Shneiderman B, Mushlin R, Karat J. Visualizing medical records with LifeLines. In: CHI 98 Conference Summary on Human Factors in Computing Systems. New York: ACM; 1998. [doi: 10.1145/286498.286513]

22.   Powsner SM, Tufte ER. Graphical summary of patient status. Lancet 1994 Aug 6;344(8919):386-389. [Medline: 7914312] [doi: 10.1016/S0140-6736(94)91406-0]

23.   Cedarbaum JM, Stambler N, Malta E, Fuller C, Hilt D, Thurmond B, et al. The ALSFRS-R: a revised ALS functional rating scale that incorporates assessments of respiratory function. BDNF ALS Study Group (Phase III). J Neurol Sci 1999 Oct 31;169(1-2):13-21. [Medline: 10540002] [doi: 10.1016/S0022-510X(99)00210-5]

24.   Alonso D. Viewing personal history records: a comparison of tabular format and graphical presentation using LifeLines. Behav Inform Technol 1998;17(5):14.

25.   Patton MQ. Qualitative Research and Evaluation Methods. 3rd edition. Thousand Oaks, CA: Sage Publications; 2002.

26.   Byrne D, Clore GL, Smeaton G. The attraction hypothesis: do similar attitudes affect anything? J Pers Soc Psychol 1986;51(6):1167-1170. [doi: 10.1037/0022-3514.51.6.1167]

27.   Norton MI, Frost JH, Ariely D. Less is more: the lure of ambiguity, or why familiarity breeds contempt. J Pers Soc Psychol 2007 Jan;92(1):97-105. [Medline: 17201545] [doi: 10.1037/0022-3514.92.1.97]

Abbreviations

ALS: amyotrophic lateral sclerosis
BiPAP: bilevel positive airway pressure
FRS: functional rating scale

<u>Original Paper</u>

Examining the Medical Blogosphere: An Online Survey of Medical Bloggers

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Abstract

Background: Blogs are the major contributors to the large increase of new websites created each year. Most blogs allow readers to leave comments and, in this way, generate both conversation and encourage collaboration. Despite their popularity, however, little is known about blogs or their creators.

Objectives: To contribute to a better understanding of the medical blogosphere by investigating the characteristics of medical bloggers and their blogs, including bloggers' Internet and blogging habits, their motivations for blogging, and whether or not they follow practices associated with journalism.

Methods: We approached 197 medical bloggers of English-language medical blogs which provided direct contact information, with posts published within the past month. The survey included 37 items designed to evaluate data about Internet and blogging habits, blog characteristics, blogging motivations, and, finally, the demographic data of bloggers.

Pearson's Chi-Square test was used to assess the significance of an association between 2 categorical variables. Spearman's rank correlation coefficient was utilized to reveal the relationship between participants' ages, as well as the number of maintained blogs, and their motivation for blogging. The Mann-Whitney U test was employed to reveal relationships between practices associated with journalism and participants' characteristics like gender and pseudonym use.

Results: A total of 80 (42%) of 197 eligible participants responded. The majority of responding bloggers were white (75%), highly educated (71% with a Masters degree or doctorate), male (59%), residents of the United States (72%), between the ages of 30 and 49 (58%), and working in the healthcare industry (67%). Most of them were experienced bloggers, with 23% (18/80) blogging for 4 or more years, 38% (30/80) for 2 or 3 years, 32% (26/80) for about a year, and only 7% (6/80) for 6 months or less. Those who received attention from the news media numbered 66% (53/80). When it comes to best practices associated with journalism, the participants most frequently reported including links to original source of material and spending extra time verifying facts, while rarely seeking permission to post copyrighted material. Bloggers who have published a scientific paper were more likely to quote other people or media than those who have never published such a paper (U= 506.5, n_1= 41, n_2= 35, P= .016). Those blogging under their real name more often included links to original sources than those writing under a pseudonym (U= 446.5, n_1= 58, n_2= 19, P= .01). Major motivations for blogging were sharing practical knowledge or skills with others, influencing the way others think, and expressing oneself creatively.

Conclusions: Medical bloggers are highly educated and devoted blog writers, faithful to their sources and readers. Sharing practical knowledge and skills, as well as influencing the way other people think, were major motivations for blogging among our medical bloggers. Medical blogs are frequently picked up by mainstream media; thus, blogs are an important vehicle to influence medical and health policy.

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KEYWORDS

Blog; journalism, medical; authorship; Internet; questionnaires; electronic publishing; medicine; podcast

Introduction

A blog (a portmanteau of Web log) is a website where entries are commonly displayed in reverse chronological order [1]. The history of blogs is closely connected with the history of the Internet itself. One of the world's first websites was started in 1992 by Tim Berners-Lee, the inventor of the World Wide Web [2], and featured a news section pointing to new websites as they came online [3]. This website can be considered the earliest predecessor of modern blogs. Most of the people who were creating websites at that time were computer experts using them as their online diaries to write about their personal lives. The actual term "Web log" was coined in 1997 and shortened to "blog" in 1999 [1]. It was not until 1999 that blogging started to become popular among a broader population of Internet users, coinciding with the launch of LiveJournal and Blogger [4,5], the first dedicated blog hosting services. These blog publishing systems allowed individuals to create and maintain their own blogs without knowing hypertext markup language (HTML). In fact today, due to the constant advancement of such blog hosting sites, people with basic computer skills can start publishing their own blogs for free in a matter of minutes.

According to report by the Pew Internet and American Life Project (Pew), published in July of 2006, 8% (12 million) of 147 million adult users of the Internet in the United States keep a blog, while 39% (57 million) read one [6]. This represents a significant increase in numbers of both writers and readers of blogs from data published a year before by the same organization [7]. Additional evidence of the persistent growth of the "blogosphere", a collective term encompassing all blogs and their interconnections, comes from the December 2007 issue of the Web Server Survey by Netcraft [8], an Internet monitoring company. This widely respected survey, that attempts to contact each and every website that is accessible on the Internet, credited blogs as the major contributor to the increase of nearly 50 million new websites in 2007 [9]. Technorati [10], the largest Internet search engine for blogs, claims to be currently tracking 112.8 million blogs, with 175,000 new blogs emerging every day.

Modern blogs have come a long way from their ancestors, evolving both technically and in terms of content. They can combine text, images, audio and video content, and links to other blogs, web pages, and other media related to their topic. Most blogs encourage feedback by allowing readers to leave comments, and it is through this knowledge sharing and debating process that they often engage a large and loyal readership. Many bloggers (blog authors) have ventured into professional journalism and have made a career out of writing blogs [11,12]. Their blogs are highly influential and are considered to be invaluable to readers who wish to follow the progress of a certain topic.

Despite their popularity, the effects of blogs, and among them medical blogs, are still largely unclear. However, it is well known that many debates originating among top medical bloggers have ended up in the pages of respectable journals, such as The New York Times, or even in news sections of the core scientific journals [13,14].

Scientific studies of medical blogs and their creators have so far been very scarce, although there is a great need for such research to help in the better utilization of blogs for the enhancement of teaching and learning productivity, advancements in scientific research, and support for continuing medical and patient education [15].

The goal of our study was to contribute to a better understanding of the medical blogosphere by investigating the characteristics of medical bloggers and their blogs. We sought to gain a better understanding of who these new medical storytellers are, what they write about, when, where, and how they do it, and finally what their motives for blogging are.

Methods

Survey

We used an online survey aimed at medical bloggers. In order to identify potential participants, we consulted 4 different websites, which aggregate medical blogs for their readers (Table 1).

We visited and took WebCite snapshots of these websites on February 10, 2007. The total number of blogs found on these websites was 740, but cross-referencing between the sources revealed 113 identical blogs, leaving us with 627 unique ones. All of these blogs were examined independently by all authors and checked against inclusion criteria, which were English-language medical blogs providing direct contact to the author, either via e-mail or online contact form, with posts published within the past month.

A medical blog was defined as a blog whose main topic was related to health or medicine. Out of the 627 listed blogs, 126 no longer existed, 10 turned out not to be medical blogs, 8 were written in languages other then English, and 152 were inactive, since their last posts were more than one month old. Eventually, a first examination of the blogs revealed 331 (53%) active and English-language medical blogs, out of which 143 (36%) were published on personal websites and 188 (64%) were published on blog hosting services. All of these blogs were once again visited and thoroughly inspected for the authors' contact information. Contact information was found on 197 (60%) of these 331 blogs (169 e-mail addresses and 28 online contact forms), which in 103 (52%) cases were hosted on personal websites and in 94 (48%) cases on blog hosting services.

Table 1. Characteristics of the websites used to identify medical bloggers and data about number of indexed blogs on February 10, 2007

Name	Web address	Description	Blog enlisting procedure	Number of indexed blogs
Medgadget	http://www.medgadget.com/archives/2006/12/the_2006_medical_blog_nominees.html	Independent on-line journal covering the latest medical gadgets and technologies, discoveries in medical science, and the progress of the digital revolution in health-care industries.	Blogs are nominated for the prestigious annual Medical Weblog Awards by the readers and verified by the editors.	118
Medlogs	http://www.medlogs.com	News aggregator for medical topics offering one of the most comprehensive listings of medical blogs available.	Readers send requests for inclusion of their blogs, which are later evaluated by the editors.	383
Trusted.MD Network	http://trusted.md/bloggers	The world's largest community of health and medical bloggers acting as a conduit for connecting bloggers with their audience and institutions.	Only registered users can add their blogs to the listing.	173
Yahoo! Directory	http://dir.yahoo.com/Health/News_and_Media/Blogs/	Human created and maintained library of websites organized into categories and subcategories.	Readers suggest a blog for a Health/News and Media/Blogs subcategory, which is then reviewed by the editors.	66

Invitations to participate in the survey were sent in 3 phases to these 197 bloggers. While 190 invitations were delivered, 5 e-mail addresses were not working and 2 online contact forms provided error messages when we tried to submit the invitation. The overall response rate was 42% (80), with 52 (65%) bloggers completing the survey after the first invitation on February 20th, 17 (21%) after the second invitation on March 7th, and 11 (14%) after the third invitation on March 22, 2007. The invitation guaranteed anonymity and confidentiality to the respondents and also informed them that the gathered data would be published in a scientific journal.

Design of the survey questions was influenced by the Pew's Blogger Callback Survey [6], with crucial modifications made to better address specific issues regarding medical bloggers and their blogs. The survey consisted of 37 questions divided into 4 parts: A – data about Internet and blogging habits (7 questions), B – data about blog characteristics (19 questions), C – data about blogging motivation (3 questions), and D – demographic data (8 questions) (see Multimedia Appendix 1 for the complete instrument).

Statistical Analyses

Pearson's Chi-Square test was used to assess the significance of an association between 2 categorical variables, for example gender and various blogging habits. Spearman's rank correlation coefficient (rho), was utilized to measure the strength of a relationship between 2 ordinal-level variables. It was used to reveal the relationship between participants' ages, as well as the number of maintained blogs, and their motivation for blogging. Finally, the Mann-Whitney U test was employed for measuring association significance of dependent variables at ordinal level and dichotomous independent variables. It was performed to reveal relationships between practices associated with journalism and participants' characteristics such as gender and pseudonym use. All statistical values were considered significant when the P value was less than 0.05. Statistical analysis of data was performed using Statistica for Windows, release 7.1 (Statsoft, Inc., Tulsa, OK, USA).

Results

Demographic Characteristics and Internet Habits

The majority of the surveyed bloggers were white, highly educated males, between the ages of 30 and 49, working in healthcare industry, and residing in the United States (Table 2).

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Table 2. General demographic characteristics of the responding medical bloggers (N=80)

Variable	n (%)
Age	
18-29	15 (19)
30-49	46 (58)
50-64	15 (19)
≥65	1 (1)
Missing	2 (3)
Gender	
Male	47 (59)
Female	25 (32)
Missing	7 (9)
Education	
Graduated high school	1 (1)
Some college	1 (1)
Graduated college	12 (16)
Some postgraduate college	8 (10)
Masters degree or doctorate	56 (71)
Missing	1 (1)
Race	
Asian	9 (11)
Black	1 (1)
White	59 (75)
Other	3 (4)
Missing	7 (9)
Country of residence	
Australia	4 (5)
India	2 (3)
Philippines	2 (3)
United Kingdom	5 (6)
United States of America	57 (72)
Other	8 (10)
Missing	1 (1)
Job title	
Faculty staff	4 (5)
Manager	14 (18)
Medical student	5 (6)
Nurse	5 (6)
Other medical profession	7 (9)
Physician	27 (34)
Researcher	4 (5)
Writer	4 (5)
Other	4 (5)
Missing	5 (7)

Variable	n (%)
Industry	
Education	7 (9)
Healthcare	53 (67)
Information	2 (3)
Media	5 (6)
Pharmaceutical	2 (3)
Other	5 (6)
Missing	5 (6)

The majority of respondents, 56% (45/80), were heavy Internet users, spending 20 or more hours per week on the Internet, with almost all (77/80, 96%) utilizing a broadband Internet connection. About 99% (79/80) of the respondents reported that they get medical news from the Internet, 86% (69/80) from other blogs, 75% (60/80) from e-mail newsletters, 63% (50/80) from Really Simple Syndication (RSS) feeds, and 24% (19/80) from podcasts. Concerning traditional news sources, 72% (58/80) of the bloggers reported that they read newspapers, 56% (37/80) read magazines, 53% (34/80) watch television, and 39% (31/80) listen to the radio to access medical news. Male bloggers used RSS feeds to get medical news more than their female colleagues (79% vs 52%, $\chi^2_1 = 4.86$, $P = .03$). Mass media and blogs together were a preferred source of medical news for 54 (70%) of the respondents, while 15 (19%) expressed a preference for mass media only and 9 (11%) only for blogs.

Blogging habits

Almost half (38/80, 47%) of the surveyed bloggers had a personal website before launching their blog. The majority of the participants can be considered experienced medical bloggers, since 23% (18/80) of them were blogging for 4 or more years, 38% (30/80) for 2 or 3 years, 32% (26/80) for about a year, and only 7% (6/80) for 6 months or less. Bloggers mainly wrote under their real name (60/80, 75%), as opposed to using a pseudonym (20/80, 25%). They preferred to write at home (64/80, 80%), rather than at work (16/80, 20%). For 35 (42%) of the participants, blog writing occupied 1 to 5 hours a week; another 22 (27%) reported that they invest 6 to 9 hours a week; and 15 (19%) bloggers reported that they write for more than 10 hours a week, while 10 (12%) of them do so for less than 1 hour a week. Most respondents had 1 blog (44/80, 55%), but there were those with 2 (17/80, 21%), and 3 or more blogs (19/80, 24%). In their main blog, more bloggers wrote about several different topics (63/80, 79%) as opposed to about only one topic (17/80, 21%) (Table 3).

Regarding the publishing of multimedia material on blogs, 63 (79%) bloggers reported that they posted photos, 60 (75%) posted images other then photos, 25 (31%) posted video files, and 26 (23%) posted audio files. RSS feeds where offered to readers by 89% (71) and e-mail newsletters by 40% (32) of blog writers. Those who got medical news from RSS feeds where more likely to offer RSS feeds to their readers ($\chi^2_1 = 9.00$, $P = .003$). Again, as in the case of receiving medical news via RSS feeds, female bloggers were less likely to offer RSS feeds to their readers than male bloggers (72% vs 98%, $\chi^2_1 = 7.39$, $P = .006$).

Table 3. Representation of main blog topics among the responding medical bloggers (N=80)

Main topic	n (%)
Health economics and policies	5 (6)
Information technology in medicine	10 (12)
Medical education	6 (8)
Medicine in general	6 (8)
Patient experience	4 (5)
Personal life	3 (4)
Pharmaceutical industry	4 (5)
Public health	9 (11)
Specific illness	8 (10)
Specific medical specialty	18 (23)
Missing	6 (8)

Journalistic activities

More than half of the responding medical bloggers have published a scientific paper (43/80, 54%), 35 (44%) bloggers have published a book or a chapter in a book, and 32 (41%) have published a newspaper article. Highly educated bloggers were more likely to have published a book or a chapter in a book (50% vs 14%, χ^2_1= 6.19, P= .01) and a scientific paper

(62% vs 21%, χ^2_1= 7.57, P= .08) than those with lower levels of education. When it comes to best practices associated with journalism, the participants most frequently reported including links to original source of material and spending extra time verifying facts, while they rarely tried to obtain permission to post copyrighted material (Table 4).

Table 4. Representation of practices associated with journalism among the responding medical bloggers (N=80)

Practice	Often n (%)	Sometimes n (%)	Hardly ever n (%)	Never n (%)	Doesn't apply n (%)
Include links to original sources	73 (91)	6 (8)	0 (0)	0 (0)	1 (1)
Spend extra time verifying facts	47 (59)	27 (34)	4 (5)	1 (1)	1 (1)
Quote other people/media directly	42 (52)	25 (31)	10 (13)	2 (3)	1 (1)
Post corrections	23 (29)	37 (46)	0 (0)	18 (22)	2 (3)
Try to obtain permission for copyrighted material	6 (7)	17 (21)	21 (27)	28 (35)	8 (10)

Female medical bloggers were found to get permission for posting copyrighted material more often than male bloggers (U= 386, n_1= 25, n_2= 44, P= .03). Bloggers who have published a scientific paper were more likely to quote directly other people or media than those who never published such a paper (U= 506.5, n_1= 41, n_2= 35, P= .016). Blog writers who were blogging under their real name were more inclined to include links to original sources than those writing under a pseudonym (U= 446.5, n_1= 58, n_2= 19, P= .01).

Motivations for Blogging

Major motivations for blogging were sharing practical knowledge or skills with others, influencing the way other people think, and expressing oneself creatively. Making money and staying in touch with friends and family were not reasons to blog for a majority of the participants (Table 5).

Table 5. Motivations for blogging of the responding medical bloggers (N=80)

Motivations for blogging	Major reason n (%)	Minor reason n (%)	Not a reason n (%)
To share practical knowledge and skills	59 (74)	19 (23)	2 (3)
To influence the way other people think	45 (56)	29 (36)	6 (8)
To express creatively	42 (53)	29 (36)	9 (11)
To document personal experiences	40 (50)	21 (26)	19 (24)
To motivate others to action	38 (48)	29 (36)	13 (16)
To store resources of information	34 (42)	24 (30)	22 (28)
To entertain people	22 (28)	32 (40)	26 (32)
To improve writing skills	21 (26)	34 (43)	25 (31)
To network or meet new people	15 (19)	33 (41)	32 (40)
To stay in touch with friends and family	9 (11)	10 (13)	61 (76)
To make money	6 (8)	23 (28)	51 (64)

Younger bloggers were more likely than their older peers to blog to improve their writing skills (r= .33, P= .049) and to write for the reason of entertaining their readers (r= .32, P= .008).

To bloggers who had more than one blog, staying in touch with friends and family was an important reason for blogging, as opposed to those with one blog (r= .31, P= .09).

Blog Attention

Almost all of the respondents received attention for their blogs from other bloggers (79/80, 99%), 78% (62/80) from their coworkers or colleagues, 66% (53/80) from news media, and 47% (38/80) from their families. Receiving family attention was more common for those who had more than one blog (63% vs 33%, χ^2_2= 7.13, P= .028). Bloggers who wrote using their real name rather than a pseudonym received more attention from their coworkers or colleagues (86% vs 58%, χ^2_1= 6.97, P= .008), as did those who got medical news from other blogs (82%

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vs 43%, $\chi^2_{1=}$ 5.89, P= .02). Three factors proved to be important in getting news media attention: more years of experience as a blogger (77% vs 48%, $\chi^2_{3=}$ 10.23, P= .02), more hours per week spent on the Internet (70% vs 30%, $\chi^2_{3=}$ 8.29, P= .04), and acquiring medical news from other blogs (71% vs 29%, $\chi^2_{1=}$ 8.72, P= .01).

Discussion

Principal Findings

Our study has shed some light on the medical blogosphere by examining the characteristics of medical bloggers and their blogs. Responding medical bloggers were highly educated and devoted blog writers, faithful to their sources and readers. Such conduct has assured them attention from other bloggers, their coworkers and colleagues, as well as the news media.

Design of our survey questions was strongly influenced by the Pew's Blogger Callback Survey [6], a well-constructed survey, which, with minor modifications, perfectly matched our needs. Furthermore, utilizing it allowed an opportunity for comparison of our bloggers with those from the Pew's survey [6]. This survey was conducted through telephone interviews between July 5, 2005 and February 17, 2006, producing a sample of 233 general bloggers from the United States. There were numerous differences between our participants and those of the Pew's survey [6]. Most of our bloggers were male, between 30 and 49 years old, with a high percentage of those holding a master's degree or a doctorate. By contrast, the majority of Pew bloggers were younger, 19-29 years of age, evenly split between genders, and less educated. These bloggers were mainly writing about their personal lives (personal diaries or journals), with only 1% of them reporting health (general health, an illness) as the main subject of their blogs [6]. Similar findings have been reported by McKenzie, who surveyed 127 writers of personal journal blogs from the United States [16]. Her respondents were also younger and less educated than our sample, but with a strong prevalence of female bloggers [16]. It might be the case that writing about demanding topics like medicine, requires a certain age, as well as a higher degree of education and experience. The fact that 75% of our medical bloggers wrote under their real name, as opposed to only 45% of Pew bloggers [6], further emphasizes their maturity.

When it comes to medical news sources, our bloggers demonstrated themselves to be avid consumers of online sources as well as traditional ones, like newspapers and magazines. Among other technically advanced social media, only podcasts were used for receiving medical news by a small percentage of medical bloggers. They are a relatively new development, so it might be that medical bloggers are still not sufficiently informed about their many benefits [15,17,18].

Responding medical bloggers demonstrated a captivating level of adherence to best practices generally associated with journalism. All of them included direct contact information on their blogs. They also included links and quoted original sources in their posts, more so than general bloggers from the Pew's survey [6]. This was especially true for those participants who

had published a scientific paper and were now successfully transferring conventions of scientific writing to their blogs. Additionally, it seems that reputation also played an important role, since those blogging under their real name followed these practices more than bloggers writing under a pseudonym.

Crucial differences, between our bloggers and those from other studies [6,16,19], were discovered regarding motivations for blogging. Sharing practical knowledge and skills, as well as influencing the way other people think, were major reasons for blogging among our medical bloggers, but not among general bloggers. A study of 177 general bloggers from Taiwan identified connecting with people and pouring out feelings to be major motivators for blogging [19]. To entertain the blogger and to allow the blogger to clarify thoughts and/or emotions were the most important reasons to blog for bloggers from the McKenzie study [16]. Staying in touch with family and friends was of great relevance to Pew bloggers [6] but not to those included in our study. Such dissimilarities could be, to a certain extent, explained by the very differences in main-blog topics. Medical bloggers responding to our survey predominantly wrote about topics aimed at their fellow colleagues, specialists in various health related fields, or patients. Only a small fraction of our bloggers constructed their blogs around their personal lives, which would be of far greater interest to their friends and families. On the other hand, those who had more than one blog identified communication with their friends and family as an important motivator. We could speculate that this is because, in blogs other than their main blog, they focus on topics aimed specifically at friends and family.

Our bloggers were extremely successful in drawing attention to their blogs. An astonishing 66% of them received attention from news media for their blogs, compared with mere 9% of Pew bloggers [6]. Responding medical bloggers offered their recipe for such success, which calls for more years of blogging, more hours spent on the Internet and getting medical news from other blogs. While persistence in blogging speaks for itself, getting medical news from other blogs is a great reminder of the importance of listening to what others have to say. It seems that news media find these popular stories originating from the blogosphere particularly interesting, perhaps because they frequently provide different and fresh perspectives.

Identifying and Contacting Medical Bloggers

Identifying medical, or any other types of blogs, and determining their exact number is a challenging and hardly-achievable task. It is unknown how many medical blogs actually exist, and their number can only be estimated from the available data. According to Technorati [10], there were 5713 blogs labeled with the "medicine" tag on May 27, 2008. However, a quick check of some of these blogs reveals that medicine is not even a remote topic of most of them. We estimate that the actual number of active and English-language medical blogs is probably closer to 1000 to 2000. This inflation of supposed medical blogs on Technorati is in part influenced by the fact that bloggers are solely responsible for assigning up to 18 tags to their blogs, for better description and visibility. Such practice puts blogs with medicine as the main topic into the same

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category as those to whom authors have assigned such a tag after 17 other, more important, and appropriate ones.

In our research, we decided to utilize more reliable sources of medical blogs, which contrary to Technorati [10], require some form of verification by the editors and moderators prior to enlisting a blog submitted by its author. Following a thorough search of the Internet and reading of numerous posts on various medical blogs, we identified 4 such websites (Table 1). After we analyzed lists of blogs from these sources and removed duplicate entries, 627 unique medical blogs were identified. Surprisingly, 46% of these blogs were found to be either inactive, with latest posts on some being written even 1 to 2 years ago, or not to exist anymore. This fact clearly demonstrates the dynamic nature of the blogosphere, where huge numbers of new blogs emerge daily only to replace the ones abandoned by their once enthusiastic authors. The credibility of the identified websites listing medical blogs thus comes into question, since it is obvious that they are not fulfilling their primary role. We believe that, with only minor revisions, substantial improvements to these websites could be made to increase the reliability of their blog directories. Such measures should, among others, include regular visits to the listed blogs and removal of those inactive for a predetermined period of time. Proposed measures could easily be performed automatically, relieving the editors and moderators of such a repetitive and weary task. For the time being it seems that the best and most reliable sources of medical blogs are actually medical blogs themselves, as most of them have lists, so called blog rolls, of their favorite blogs. This was also confirmed in our study, since the most useful source among those we consulted, turned out to be a blog named Medgadget [20]. Only 2 out of 118 blogs nominated by other medical bloggers for the annual Medical Weblog Awards on Medgadget were demonstrated to be incorrect [21].

Almost all of the blogs we identified allowed their readers to post comments, but only 59% included the author's e-mail address or an online contact form. Such a low percentage was somewhat unexpected, but it could be that bloggers felt the comment sections were sufficient enough for discussion and communication with their readers. Fear of spam messages is probably another reason why so many chose not to reveal their e-mail addresses. We noticed that a lot of bloggers who did provide them employed some sort of method, for example putting spaces in their e-mail addresses, intended to deceive spambots, which are automated computer programs collecting e-mail addresses from the Internet. Interestingly, bloggers who hosted blogs on their own personal websites more frequently provided direct contact information than others who used blog hosting services. These bloggers probably have considerable web programming skills and demand greater freedom and flexibility than the blog hosting services have to offer. Since the whole website is a product of their work and creativity, including contact information, if for nothing other than recognition, seems natural. Survey invitations were sent directly to selected bloggers, rather than being posted to comment sections of their latest blog posts, because we wanted only these bloggers to participate in the survey. It is easily conceivable that other medical bloggers not included in our sample could

have, after reading such an invitation in comment sections of other blogs, decided to fill out the survey. This would completely disrupt the design of our study, as we would not know who our participants were, and whether their blogs met our inclusion criteria.

Limitations and Future Studies

There were several limitations in our study, mainly concerned with our strategy of blog inclusion. At the time we conducted our research there were no comprehensive directories of medical blogs for us to use. Available websites listing medical blogs proved to have many drawbacks. Furthermore, a substantial number of bloggers were excluded from our study because direct contact information was not included in their blogs. Bloggers to whom we eventually sent survey invitations, replied in good numbers, but in lower numbers than we expected. We can speculate that such a response rate could be to some degree a consequence of overwhelming influx of data daily cramming their e-mail inboxes in which some interesting pieces of information can easily be overlooked. It would be useful for future research to conduct a follow up study to identify reasons why so many invited bloggers chose not to participate in the survey. We plan to ask bloggers to whom we originally sent invitations these questions when we notify them about the publication of our results.

During the course of the survey, many bloggers have contacted us to express their enthusiasm and compliment our efforts. Most importantly, all of them were very interested to see the results upon completion of the survey. Some even made it a condition of their participation in the survey that study results would be freely available. Bloggers are great supporters of open access to information, and this is one of the main reasons why we chose an open-access journal to publish our results. Hopefully their experience with our survey will make them more confident of similar research in the future.

It is clear that our results represent only bloggers who participated in the survey and may likely be skewed towards those who practice good blogging habits. Furthermore, we cannot be sure whether our respondents adequately represent all medical bloggers. Since this was a cross-sectional study, and given the fact that the blogosphere is highly dynamic, our results only present the situation at the time of the survey. Future studies should continue to evaluate medical bloggers and their blogs, presumably with larger numbers of participants included in prospective studies. These studies should also include blog-content analysis, as well as an investigation of the characteristics of blog readers. Additionally, survey questions should be further advanced. There should be more questions regarding the social, rather than technical, aspect of blogs, such as questions about the relationship with readers. Before such research can be successfully coordinated, the issue of medical blog directories, as depicted in our study, should be meticulously addressed. Recently, several new blog directories have emerged which have solved some of the issues mentioned in our study and may prove to be highly valuable for future studies [22,23]. Last, but not least, we are looking forward to see more research on medical blogs written in languages other than English to disclose their particularities and impact on local communities.

Conflicts of Interest

One of the authors (IK) used to contribute as an associate editor to Medgadget [20], an international journal of emerging medical technologies and one of the top medical blogs, back in 2005 and 2006. He now writes his own blog, Ivor Kovic MD [24].

Multimedia Appendix 1

37-item medical bloggers survey used in the study

[HTML file (HyperText Markup Language), 34 KB - jmir_v10i3e28_app1.html]

References

1. Blog. Wikipedia, the Free Encyclopedia. URL: http://en.wikipedia.org/wiki/Blog [accessed 2008 Jul 27] [WebCite Cache ID 5Zikn1mH2]
2. Tim Berners-Lee. Wikipedia, the Free Encyclopedia. URL: http://en.wikipedia.org/wiki/Tim_Berners_Lee [accessed 2008 Jul 27] [WebCite Cache ID 5ZikroVnm]
3. Berners-Lee T. What's New in '92. WC3. URL: http://www.w3.org/History/19921103-hypertext/hypertext/WWW/News [accessed 2008 Jul 27] [WebCite Cache ID 5ZikuXIFk]
4. Start a Free Blog/Journal Today. LiveJournal.com. URL: http://www.livejournal.com [accessed 2008 Jul 27] [WebCite Cache ID 5ZikxnZdQ]
5. About Blogger. Blogger. URL: http://www.blogger.com/about [accessed 2008 Sep 23] [WebCite Cache ID 5b30pVZS6]
6. Lenhart A, Fox S. Bloggers: A portrait of the internet's new storytellers. Washington, DC: Pew Internet & American Life Project; 19, 2006. URL: http://www.pewinternet.org/pdfs/PIP%20Bloggers%20Report%20July%2019%202006.pdf [accessed 2008 Jul 27]
7. Rainie L. The state of blogging. Washington, DC: Pew Internet & American Life Project; 2005. URL: http://www.pewinternet.org/pdfs/PIP_blogging_data.pdf [accessed 2008 Jul 27]
8. Internet Research, Anti-Phishing and PCI Security Services. Netcraft Ltd. URL: http://news.netcraft.com/ [accessed 2008 Jul 27] [WebCite Cache ID 5b1qO1usj]
9. December 2007 Web Server Survey. Netcraft Ltd. URL: http://news.netcraft.com/archives/2007/12/29/december_2007_web_server_survey.html [accessed 2008 May 27] [WebCite Cache ID 5az6gUriI]
10. What's Percolating in Blogs Now. Technorati. URL: http://www.technorati.com [accessed 2008 Jul 27] [WebCite Cache ID 5az6nHRYK]
11. NxE's Fifty Most Influential Bloggers. North x East. URL: http://northxeast.com/blogging/nxes-fifty-most-influential-bloggers/ [accessed 2008 Aug 20] [WebCite Cache ID 5amDdc36D]
12. My Son, the Blogger: An M.D. Trades Medicine for Apple Rumors. The New York Times. URL: http://www.nytimes.com/2008/07/21/technology/21blogger.html [accessed 2008 Aug 20] [WebCite Cache ID 5az6x75q3]
13. Coombes R. Who are the doctor bloggers and what do they want? BMJ 2007 Sep 29;335(7621):644-645. [Medline: 17901512] [doi: 10.1136/bmj.39349.478148.59]
14. Giustini D. How Web 2.0 is changing medicine. BMJ 2006 Dec 23;333(7582):1283-1284 [FREE Full text] [Medline: 17185707] [doi: 10.1136/bmj.39062.555405.80]
15. Boulos MNK, Maramba I, Wheeler S. Wikis, blogs and podcasts: a new generation of Web-based tools for virtual collaborative clinical practice and education. BMC Med Educ 2006;6(1):41 [FREE Full text] [Medline: 16911779] [doi: 10.1186/1472-6920-6-41]
16. McKenzie HM. Why Bother Blogging? Motivations for Adults in the United States to Maintain a Personal Journal Blog [master's thesis]. Raleigh, NC: North Carolina State University; 2008 65pp.
17. Savel RH, Goldstein EB, Perencevich EN, Angood PB. The iCritical care podcast: a novel medium for critical care communication and education. J Am Med Inform Assoc 2007;14(1):94-99 [FREE Full text] [Medline: 17068348] [doi: 10.1197/jamia.M2205]
18. Rowell MR, Corl FM, Johnson PT, Fishman EK. Internet-based dissemination of educational audiocasts: a primer in podcasting—how to do it. AJR Am J Roentgenol 2006;186(6):1792-1796. [Medline: 18562712] [doi: 10.2214/AJR.05.1315]
19. Liu SH, Liao HL, Zeng YT. Why people blog: an Expectancy Theory analysis. Issues in Information Systems 2007;8:232-237.
20. Internet Journal of Emerging Medical Technologies. Medgadget.com. URL: http://www.medgadget.com [accessed 2008 Jul 27] [WebCite Cache ID 5b1qjfL9L]
21. The 2006 Medical Weblog Awards Nominees. Medgadget.com. URL: http://www.medgadget.com/archives/2006/12/the_2006_medical_blog_nominees.html [accessed 2008 Sep 23] [WebCite Cache ID 5b2TrV0N5]
22. Healthcare 100 – Ranking the World's Top Blogs and Bloggers in Health and Medicine. eDrugSearch.com. URL: http://www.edrugsearch.com/edsblog/healthcare100 [accessed 2008 Jul 27] [WebCite Cache ID 5az7B2tvQ]
23. MedBlogEN. MedBlog.nl. URL: http://medblog.nl/medblogen [accessed 2008 Jul 27] [WebCite Cache ID 5az7FwY3g]

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24.   Ivor Kovic MD (Blog). URL: http://www.ivor-kovic.com/blog [accessed 2008 Sep 20] [WebCite Cache ID 5az7Qwsol]

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Original Paper

SOMWeb: A Semantic Web-Based System for Supporting Collaboration of Distributed Medical Communities of Practice

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Abstract

Background: Information technology (IT) support for remote collaboration of geographically distributed communities of practice (CoP) in health care must deal with a number of sociotechnical aspects of communication within the community. In the mid-1990s, participants of the Swedish Oral Medicine Network (SOMNet) began discussing patient cases in telephone conferences. The cases were distributed prior to the conferences using PowerPoint and email. For the technical support of online CoP, Semantic Web technologies can potentially fulfill needs of knowledge reuse, data exchange, and reasoning based on ontologies. However, more research is needed on the use of Semantic Web technologies in practice.

Objectives: The objectives of this research were to (1) study the communication of distributed health care professionals in oral medicine; (2) apply Semantic Web technologies to describe community data and oral medicine knowledge; (3) develop an online CoP, Swedish Oral Medicine Web (SOMWeb), centered on user-contributed case descriptions and meetings; and (4) evaluate SOMWeb and study how work practices change with IT support.

Methods: Based on Java, and using the Web Ontology Language and Resource Description Framework for handling community data and oral medicine knowledge, SOMWeb was developed using a user-centered and iterative approach. For studying the work practices and evaluating the system, a mixed-method approach of interviews, observations, and a questionnaire was used.

Results: By May 2008, there were 90 registered users of SOMWeb, 93 cases had been added, and 18 meetings had utilized the system. The introduction of SOMWeb has improved the structure of meetings and their discussions, and a tenfold increase in the number of participants has been observed. Users submit cases to seek advice on diagnosis or treatment, to show an unusual case, or to create discussion. Identified barriers to submitting cases are lack of time, concern about whether the case is interesting enough, and showing gaps in one's own knowledge. Three levels of member participation are discernable: a core group that contributes most cases and most meeting feedback; an active group that participates often but only sometimes contribute cases and feedback; and a large peripheral group that seldom or never contribute cases or feedback.

Conclusions: SOMWeb is beneficial for individual clinicians as well as for the SOMNet community. The system provides an opportunity for its members to share both high quality clinical practice knowledge and external evidence related to complex oral medicine cases. The foundation in Semantic Web technologies enables formalization and structuring of case data that can be used for further reasoning and research. Main success factors are the long history of collaboration between different disciplines, the user-centered development approach, the existence of a "champion" within the field, and nontechnical community aspects already being in place.

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Introduction

Motivation

Oral medicine is a subdiscipline of dentistry concerned with diseases related to the oral and paraoral structures, including the principles of medicine related to the mouth as well as diseases specific to the orofacial tissues and oral manifestations of systemic diseases. Oral medicine is a quite small and growing subdiscipline. It often deals with disorders of low prevalence, and to enhance the knowledge, gathering of clinical data from large geographic areas is needed. This means that cooperation between geographically distributed clinics is vital for providing a means of consultation and learning for a broader audience and for collecting diverse and numerous cases for further analysis and teaching.

The Swedish Oral Medicine Network (SOMNet) promotes knowledge sharing and dissemination between clinicians and researchers in oral medicine in Sweden. The central activity of SOMNet is regularly held distributed meetings focused on case discussions. These meetings are conducted using telephone conferences. The cases to be discussed are distributed among SOMNet members before the meetings. Before the introduction of the system presented here, cases were presented as PowerPoint presentations, which were emailed prior to the meetings. As the number of participants grew, emailing was abandoned in favor of an online repository of presentations converted to HTML. Several drawbacks with this solution were identified, such as the lack of connection between follow-up presentations and the original case, no common structure for information entered, and no support for searching and browsing the cases. This led to considerations of developing an online solution more tailored to the needs of SOMNet that should complement the speech-based interaction with Internet-supported management of structured case descriptions and images.

Modern information technology (IT) in general and the Internet in particular provide the technical infrastructure for supporting interdisciplinary clinical teamwork [1]. Benefits include the possibility of distance consultation and accessing remote expertise [2], sharing clinical data and imagery, dissemination of information and knowledge through broadcasted seminars and online courses [3], and distributed virtual work places [4]. Internet and IT are of course prevalent within eHealth. However, so far, most work has been on telemedicine and consumer health informatics, and the utility of eHealth systems to promote clinical teamwork and collaboration has received little attention [1,3]. Even more so, given the current focus on evidence-based medicine [5], the need for research on how daily clinical practice can be used as a basis for further scientific activities within a distributed medical community is eminent [3,6].

The design, development, and adoption of IT-supported tools for clinical activities within distributed medical communities is a sociotechnical problem [7,8], requiring more research on the communication and knowledge processes used by community members in everyday practice and research [1,9], social and behavioral factors influencing the adoption and use of tools [3,10], and research on how to take full advantage of the capacities of the Internet and the computer as essentially new media for conducting clinical practice and medical research [11-13].

One way to promote the knowledge sharing and dissemination is to provide IT support for communities of practice (CoP). A community of practice is a group of people who share "a concern, a set of problems, or a passion about a topic, and who deepen their knowledge and expertise in this area by interacting on an ongoing basis" [14]. Of special interest is the possibility of using the Internet to support virtual CoP, where members are geographically dispersed and where face-to-face meetings are rare. A virtual CoP has at its disposal both traditional media, such as telephone and telephone conferences, as well as more recent technological tools, such as email, databases, websites, and online meeting places [15]. Internet-based CoP can play an important role in the externalization of tacit knowledge of the individual (eg, clinical practice knowledge) into explicit and diffused knowledge (eg, evidence, protocols, or clinical guidelines) [16].

Semantic Web technologies have been put forward as enablers of Internet-based tools supporting knowledge-intensive tasks [15,17]. A key component of the Semantic Web is the representation of knowledge in a computer-processable manner, in the form of ontologies [18]. However, despite much effort, the adoption of ontologies within the medical domain has turned out to be more problematic and slower than many had hoped [19], and there is a need for successful examples showing how Semantic Web technologies can be put to use.

In terms of online health information systems, interactivity and end-user control are instrumental in creating "a sense of mutuality, connection, common ground, and shared understanding, and, ultimately, participation in medical decision making" and for enhancing "elaboration and learning of complicated concepts that require understanding linkages between concepts" [13]. Poor interface design and tools not being well adapted to the tasks at hand and not seamlessly integrated into workflows are causes of failure of medical collaboratories [3]. Development of tools in collaboration between user and developer, where prototypes are tested in the daily clinical activity, has been identified as a key success factor in the development and adoption of health information systems [20,21]. Tools should be simple and adaptable to the individual user's preferences and needs [22].

Aims and Objectives

The aims of the presented research are to acquire (1) a better understanding of how clinicians in oral medicine communicate and collaborate, (2) more knowledge about the design, development, and adoption of Internet-based tools for distributed

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clinical practice, learning, and research, and (3) experience in applying Semantic Web technologies to realistic examples.

These aims are reached by fulfilling the following objectives: (1) study the communication of distributed health care professionals in oral medicine, within the framework of CoP; (2) apply Semantic Web technologies to describe community data and oral medicine knowledge; (3) design, develop, and adopt an online CoP of oral medicine (SOMWeb) centered around user-contributed case descriptions and meetings, which, in order to increase user acceptance, should be user-centered and user-controllable and should be based on iterative testing and validation of the computer support in daily clinical work; (4) evaluate the online CoP and study how communication and work practices change with IT support.

Methods

Study Context

SOMNet was initiated in the early 1990s to share oral medicine knowledge and make possible consultations in a fairly small discipline where clinics are geographically dispersed. SOMNet can also be seen as an instrument for continuing education, for harmonizing terminology, and for building a database of interesting cases in oral medicine. The participants are distributed throughout Sweden, in clinics at hospitals, primary care facilities, and in private practice. The members of SOMNet are mainly dentists with an interest in oral medicine. Some, but not all, of the participants have been certified by the Swedish Oral Medicine Society (SOMS). Among the participants are general practitioner dentists, hospital dentists, specialists in jaw surgery and oral medicine, professors, and some oral pathologists.

SOMNet's members have had access to different generations of IT support for their teleconferences. To identify drawbacks with the previously described PowerPoint-based solution and come up with requirements for a new system, we observed meetings, interviewed several members, and used an online questionnaire. The observations were done at the clinic of oral medicine, at the Sahlgrenska Academy in Gothenburg. Among the identified needs were the ability to add cases in a more structured manner, to assign cases to meetings both for initial consultation and for follow-up, to view cases allocated to a given meeting, and to search and browse the case repository.

The SOMWeb system was constructed to provide the above functionality. SOMWeb was developed in cooperation with clinicians starting in spring 2005 and was introduced to all SOMNet members in May 2006. Our primary contact is the clinic for oral medicine at Sahlgrenska Academy in Gothenburg. This is a continuation of more than 10 years of collaboration during which a suite of software, called MedView, has been developed to support the oral medicine clinicians [23].

In SOMWeb, no information is available that will reveal the identity of the individuals in the presented cases. The case data that each presenter has to provide do not contain personal information, except for age, gender, and ethnic background. *En face* images are prohibited, and intraoral images will not disclose identity. All members of SOMNet have signed a professional secrecy agreement as part of their clinical assignment. In addition, all users need an individual username and password in order to access the system.

Methods of System and Ontology Development

System Development

In order enhance user acceptance and system usability, SOMWeb was developed iteratively, following a user-centered design approach, which means that already from the start, a select group of users were involved in the design process [20]. The users took part in the establishment of initial requirements and have continuously provided feedback on developed prototypes.

Figure 1. A paper prototype of SOMWeb that shows a text-based search function, restricted to a specified clinic and clinician, which results in a list of cases with associated photos shown as thumbnails, with the option of viewing and editing case data
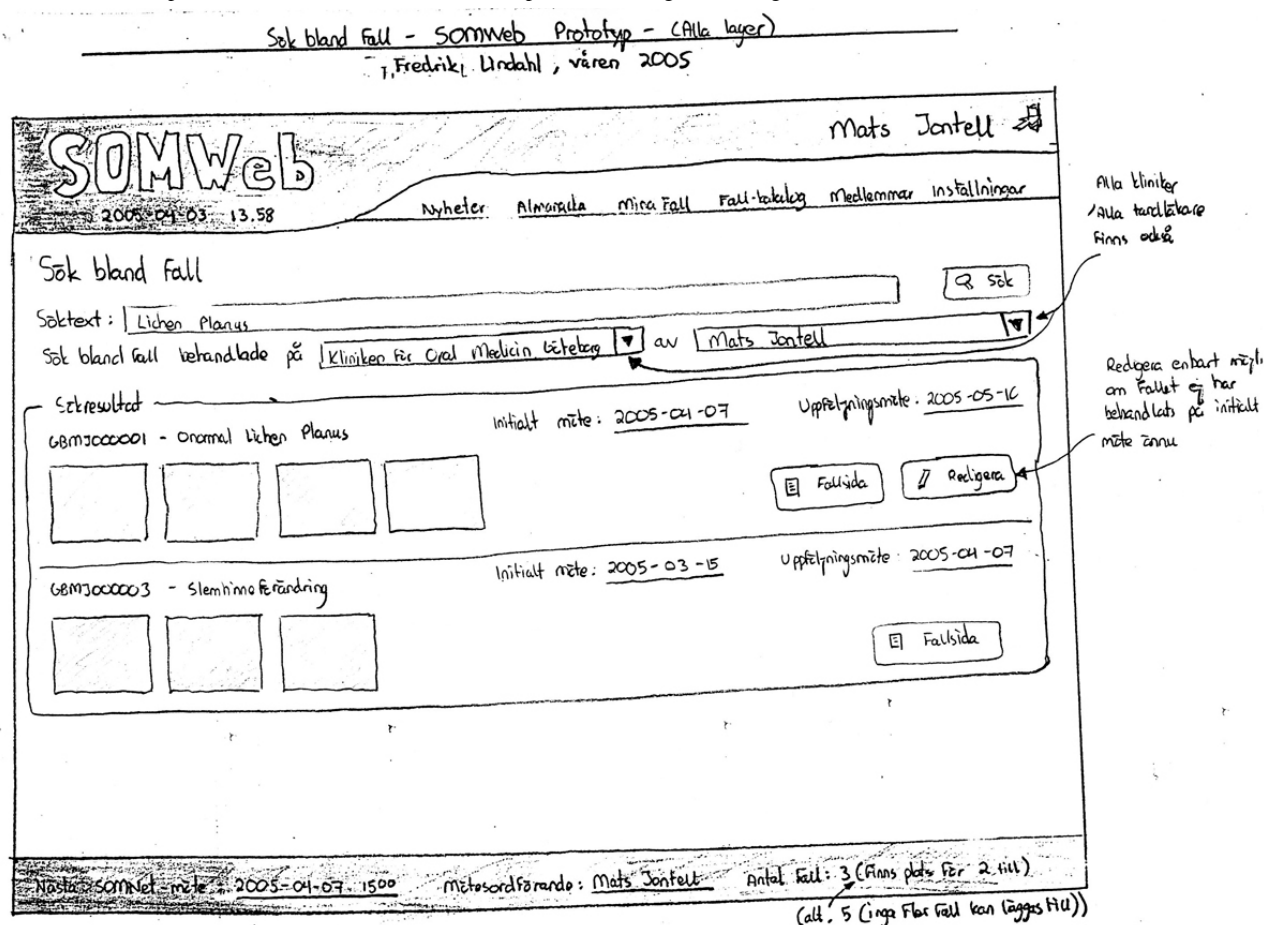
As a first step toward replacing the old method of distributing case presentations, a simple Web page was created where submitted cases were made available to members of SOMNet. In parallel, paper prototypes were developed as they are an efficient means to provide initial presentation of a system to users (see Figure 1 for an example). Based on discussions with the user group, an interactive HTML prototype was developed. This prototype, while not containing any real functionality, was fully testable and provided the opportunity to try out what it would be like to work with the system (Figure 2).

The presentation of the prototypes led to deep and lengthy discussions with the user group concerning the exact details of what should be included in the system, how cases should be presented and entered, how follow-up cases should be handled, and so on. Once initial consensus was reached based on the

prototypes, development of the first version of the system began. According to the iterative development method, only the basic functionality for adding cases and managing these at meetings was implemented at first. In a later iteration, secondary features like email messaging and a discussion forum were added to the system.

The design rationales are to provide simplicity of interaction and a clean and esthetically attractive user interface design. This was to avoid often-reported problems with medical information systems not having compelling and useful interfaces for the user [24,25]. It was also our experience from previous work that the IT-maturity among clinicians is not very high. To ensure simplicity, only basic functionality is initially available. To have full access to all parts of the system, the users must make an active choice by changing their individual preferences.

Figure 2. The first HTML prototype of SOMWeb showing a meeting page with new cases to be discussed for the first time and cases that are follow-ups from previous meetings, with photos for each case displayed as a row of thumbnails
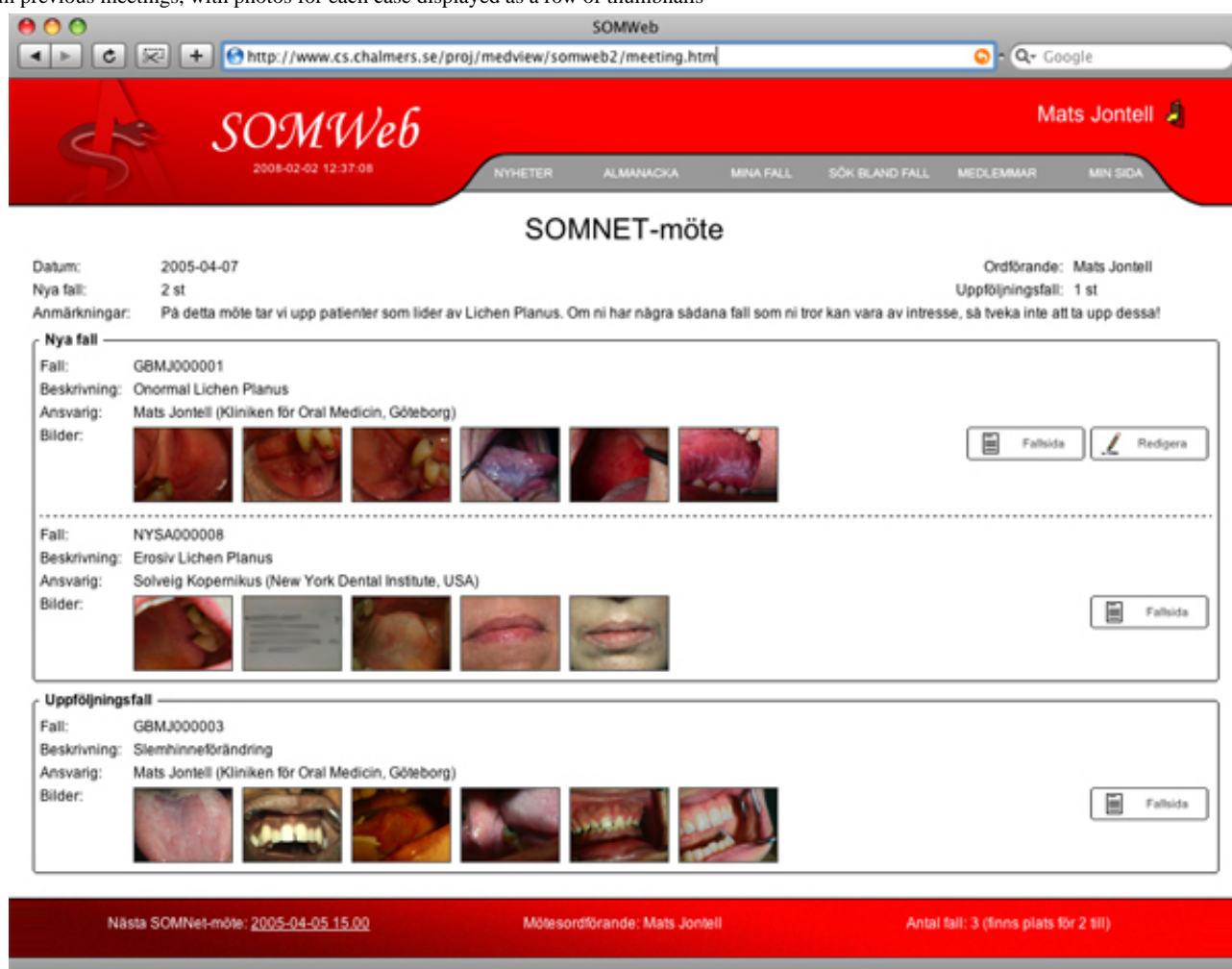
From a technical point of view, we have used object-oriented software development methods, such as the Unified Process (UP/RUP), and the Unified Modeling Language according to established design patterns. SOMWeb is built on the Apache Struts Model-2 Web application framework. In Model-2 frameworks, a variation of the classic model-view-controller design paradigm, Java servlets execute business logic with server pages handling the presentation.

Ontology Development

Ontologies are used in SOMWeb to represent oral medicine templates and knowledge, as well as to represent community models and data. The Web Ontology Language (OWL) and Resource Description Framework (RDF), which became a World Wide Web Consortium (W3C) recommendation in February 2004, are used. The knowledge representation and content of MedView are taken as starting points in the design of the oral medicine ontologies of SOMWeb. The OWL ontologies were automatically generated from the previous representation, after extensive work in identifying appropriate corresponding OWL constructs. Identifying external sources for reusing medical knowledge was attempted, but none was found with the appropriate focus. Ontology elements related to community aspects were identified through the iterative modeling and

development work described above. For reading and writing OWL and RDF from Java, the Jena programming API was used.

Methods for Studying Community Collaboration and System Evaluation

Our study of SOMNet's collaboration and the use of SOMWeb include interviews with participants, observations of teleconference meetings, and an online questionnaire.

The interviews were intended to provide a greater understanding of how SOMWeb is used and how it has affected SOMNet's meetings and the members' knowledge use and to identify processes that are part of SOMNet functioning as a distributed CoP. A semistructured interview format was chosen in order to have the flexibility to adapt the interview to the issues brought up by the interviewee. Interviews were thus guided by a semistructured interview guide, which included sections about submitting cases, meeting participation and preparation, knowledge needs and benefits of SOMNet, and use of the SOMWeb system outside of meetings. Questions regarding the addition of cases asked about how the interviewee decides to add a case, how he or she gathers information about the case, and opinions about the form used for entering cases. Regarding meetings, questions asked about how the meetings had changed since using PowerPoint, when the system works well and when it does not work during meetings, how often the interviewee

participates and how he or she usually prepares for meetings. Regarding knowledge needs, interviewees were asked about their own benefit in participating in SOMNet, how they perceived the benefit of others, what kind of cases they thought SOMNet should include, and if there was an example of when SOMNet has helped solve a case that might not have been resolved otherwise. Interviewees were also prompted for whether there was anything they wanted to discuss that was not brought up in the questions. The questions were not always brought up in the same order.

We interviewed nine members of SOMNet. Five were interviewed individually, and two interviews were carried out with two members at a time. The first interview was carried out in November 2007 and the last in March 2008. Each interview lasted between 35 and 85 minutes. Three of the interviewees have been members more or less from the start, three have been members for at least 4 years, and three have joined more recently. Two of the respondents are oral pathologists and do not see patients themselves. The other seven all work at hospitals, and two of these have a research background.

Interviews were recorded and transcribed. The questions for the interview were used as initial themes for coding the interviews, but matter that came up spontaneously during interviews was also included in the coding. The interviewer carried out all coding, first by hand on printed transcripts and then by collecting responses from interviewees in a spreadsheet. This compilation was used to compare and count interviewee opinions on different themes. However, due to the qualitative nature of the study and the open-ended responses, a deeper quantitative analysis is not appropriate.

Observations are carried out by sitting at one of the clinics during a telephone conference. The purposes of the observations were to elucidate how cases are presented during teleconference meetings, how clinicians behave locally during these meetings, and how the SOMWeb system is used locally during meetings. The same person did all observations. Notes were taken on both what was said in the telephone conference as a whole and on what the participants said and did locally. One meeting was also recorded and transcribed. In analyzing the data, descriptions of the meeting procedure and case presentations were generalized from notes. Ten meetings were observed: six at the clinic for oral medicine at the Sahlgrenska Academy in Gothenburg and four at four other clinics in Sweden. The first meeting was observed in February 2007 and the last in April 2008.

The online questionnaire contained both open-ended and closed-ended questions. In the first category were questions about reasons for participating and choosing to add cases; in the latter were questions for comparing the SOMWeb system to the PowerPoint-based approach along several facets, such as submitting cases and viewing old cases, where a scale of better, neutral, or worse was used. The questionnaire was made available for about one month in the spring of 2007. Requests for completing the questionnaire were made at a telephone conference, on the news page of the system, and by email to around 60 members, the total number of members at the time. In total, 24 members completed the questionnaire.

Since these observations were carried out by one of the developers of the SOMWeb system, there could be bias both in what the developer observes and in the behavior of the users when observed. This also applies for the interviews. Brender [26] describes pitfalls and biases related to the use of questionnaires and interviews, including psychological factors leading to unwillingness to answer questions due to factors such as prestige, differences between personal opinions and the official account, and mood at the time of responding.

Results

The results include characteristics of collaboration as studied through the use of SOMWeb, the SOMWeb system, and evaluation aspects pertaining more directly to the system.

Communication and Collaboration Within SOMNet

Meeting Structure and Activities

The SOMNet distance consultations are held once a month (five times in the spring and four times in the fall) by telephone conference. The time scheduled for each meeting is one hour, during which three to six cases are brought up for the first time, and up to three are presented as follow-up cases. A chairperson leads the meeting, for example, by providing transitions between case presentations and by leading and summing up discussions. When presenting a case, the presenter often tells the story of his or her meetings with the patient, treatments tried, and results of these treatments. After, and sometimes during, this short presentation, the other participants ask questions for clarification. Depending on the kind of case presented and what purpose the clinician had for wanting to discuss it, the participants will start suggesting possible diagnoses and treatments. Similar cases or general treatment strategies will sometimes accompany the suggestions. A more broad discussion may ensue, for example, about reported side effects for medications or whether a certain treatment is suitable in general. The chairperson usually starts summarizing when several options have been put forth, and suggestions are given to the presenter. Few participants, apart from the chairperson, took notes at the meetings that were observed.

SOMNet has a lot of experience with teleconferences, and there is a flow in the conversation even though participants cannot see each other. Most participants indicate who is speaking before giving their comment. However, if somebody chooses to have a small local discussion, the flow in conversation is quicker and more interactive.

As of May 2008, 10 to 15 clinics join each meeting. At each of these, there are between one and 10 participants, with an average of three. Where the participants at a local clinic congregate for a teleconference meeting depends on how many participants there are. If only a small number, then they usually sit in front of a computer in an office. If there are more than two or three participants, then usually a meeting room with a projector is used.

Meeting Preparations

All interviewees replied that they usually go through the cases before the meeting, either the same day or the night before.

While doing this they try to form their own opinion of the cases and find that the benefit of participation increases with this preparation. It was also indicated that there is an obligation toward the case submitter to look at the case before the meeting. The designated chairperson makes a more thorough review of the meeting's cases and tries to find relevant research literature. Some also add private comments to cases.

A problem brought up is that the cases are submitted too late, which makes it difficult for the members and especially the chairperson to prepare.

Purposes for Presenting Cases

Interview responses and observations indicated mainly three purposes for presenting cases: cases where advice regarding diagnosis or treatment is wanted, cases of an unusual character, and cases where the presenter wants to raise an issue for discussion. The advice seeking is most common, but the presenter may have several reasons for bringing a case to the meeting. Examples of recurring discussions are how to monitor patients with precancerous disorders and the reporting of medication side effects.

Individual Member and Community Benefits

The value of SOMNet for the majority of participants is access to external expertise and, in the end, better care for patients, in addition to a means of continuing education. Interviewees brought up concrete examples of when they benefited from diagnosis and treatment discussions at meetings, both for cases they presented themselves and from discussions of others' cases. For example, one respondent described how a special kind of plastic guard described at the meeting had been constructed and used with good results. Another respondent reported how the same technique had been related to, and later applied by, a dentist at a nonparticipating clinic. A third respondent vividly retold the lengthy discussion generated by a difficult case where the symptoms could be construed to have three different causes. Members that are more senior find SOMNet valuable for getting references and comparative material, while maintaining competency and enthusiasm. Meanwhile, the pathologists, with no patients of their own, bring up the social aspects SOMNet provides, in addition to a more complete clinical picture of patients than they usually get. Members at teaching institutions have also included participation in SOMNet as a part of the curricula of some of their courses.

Identified Barriers and Issues

The interviewees often raised the issue of a lack of time due to a heavy load of patients or teaching. One interviewee brought up the differences that he feels exist between his work place, where oral medicine is a small part of the overall activities and where there is no research connection, and research institutions with a specialty in oral medicine. He found that it was not possible to set aside office hours to search for and read relevant literature. Fortunately, there were no problems in setting aside an hour for the meeting.

While interviewees at research institutions and some hospitals had access to online articles, smaller hospitals and general practitioners often lacked such access. Interviewees who mainly see patients state that they do not use literature as much as they would like with, again, time being the main barrier. Two interviewees indicated that reading articles was mainly done outside of work hours.

Another matter discussed in interviews was how the participation of smaller clinics can be increased, regarding both contributing cases and participating verbally in the meetings. Connected with this is how the concern about exposing gaps in one's knowledge can be alleviated. This is also related to what kinds of cases are submitted by the more active case presenters, and some replies to the questionnaire stated that they had considered entering a case but came to the conclusion that it was not "advanced enough." When this was brought up in interviews with the more active participants, several said that meeting discussions around what appeared to be straightforward cases to them usually turned into very interesting discussions, or as one of the most senior members said, "There isn't one case that is not interesting enough."

The SOMWeb System for Community Collaboration

SOMWeb Community Functionality

The first page a member sees after logging in is a news page (Figure 3), where administrative users put information relevant to all members. Navigation in SOMWeb is done mainly through a menu on the left, with subheadings for main functionality: meetings, cases, communication, and members.

Figure 3. News page with information for all members
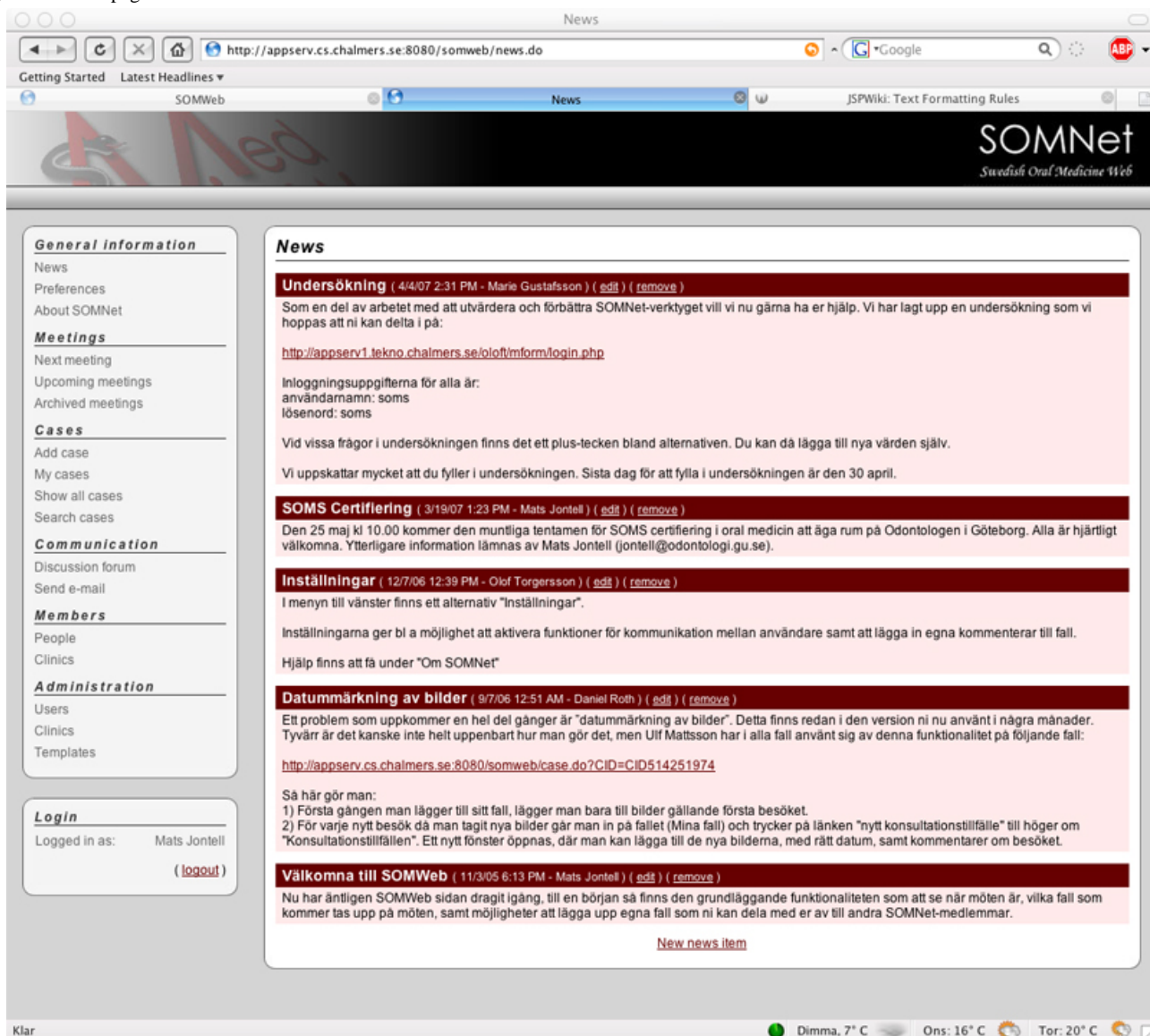
Under the meetings subheading, there is a link to the current meeting and to lists of past and future meetings. A meeting page (Figure 4) displays the meeting's date and designated chairperson. It also shows a listing of cases added for discussion at this meeting, which is divided into cases to be discussed for the first time and those to be followed up from previous meetings. For each case in the list, its owner and and a descriptive case title are provided, as well as a link to the case presentation page.

Figure 4. Meeting page with date, chairperson, and list of cases added for discussion at the meeting

From the cases subheading, a user can add a case, display a listing of all cases, and access a free-text search of all cases. When wanting to add a case, the user is presented with a blank form (Figure 5), generated from a consultation template, the formalization of which is described in the next subsection. The form includes questions about, for example, current medications and tried treatments, and for each question, a list of allowed values is shown. If a value is missing, the user may enter it into the value list. The form also includes a free-text section. Images associated with the case are also submitted with this form. After adding a case, the user can assign it to be discussed at an upcoming meeting. A meeting for follow-up discussion can also be specified.

Figure 5. A form for adding a new case based on a user-defined consultation template

All submitted cases generate a case presentation page (Figure 6), which begins with administrative data: the case owner with affiliation, a short description provided by the owner, and any assigned meetings. Then, the case's consultations are displayed. For each consultation, thumbnails of associated images are shown along with a presentation generated from the consultation

data. From these thumbnails, a larger image browser can be accessed. Each case consists of a number of consultation occasions, and there are currently three different types of consultations: for initial case entry, for follow-up data, and for recording suggestions from meetings. These have separate entry forms with associated templates. All users can add follow-up consultations to cases, to make it possible for pathologists to add images and for users at the same clinic to share a case. Only the chairperson of a meeting can add notes to cases with suggestions from the meeting. All users can also add support material to cases, both in the form of articles and more generally related material such as images from a similar case. When entering an article, there is a facility for searching PubMed and automatically retrieving relevant article details.

A user can also choose to add private notes to cases. If a discussion thread exists for the case, it can be accessed from the presentation. If not, then clicking a link creates a new thread.

Figure 6. Case presentation page listing administrative data, consultation occasions with summarized case data and associated images, and related material

Browsing cases can be done via the meeting pages, pages listing cases of individual members, the list of all cases, or results of searching. From the "Members" subheading, users can access listings of all members and the clinics to which they belong, along with contact details.

A discussion forum listing all case discussions is located under the communication subheading. The users can also create threads not related to cases. Another communication facilitated by SOMWeb is reaching other clinicians by email. Messages can be sent directly from SOMWeb either from the communication subheading or to the case owner from a case presentation page.

It should be noted that SOMNet members have influence over the form of content and presentation of cases. First, case templates determining what information should be collected from submitted cases are the result of agreement between community members. As their needs change, they can update the templates themselves, using an editor in which they never interact with the underlying case representation. Second, summaries of cases are generated from stored data using
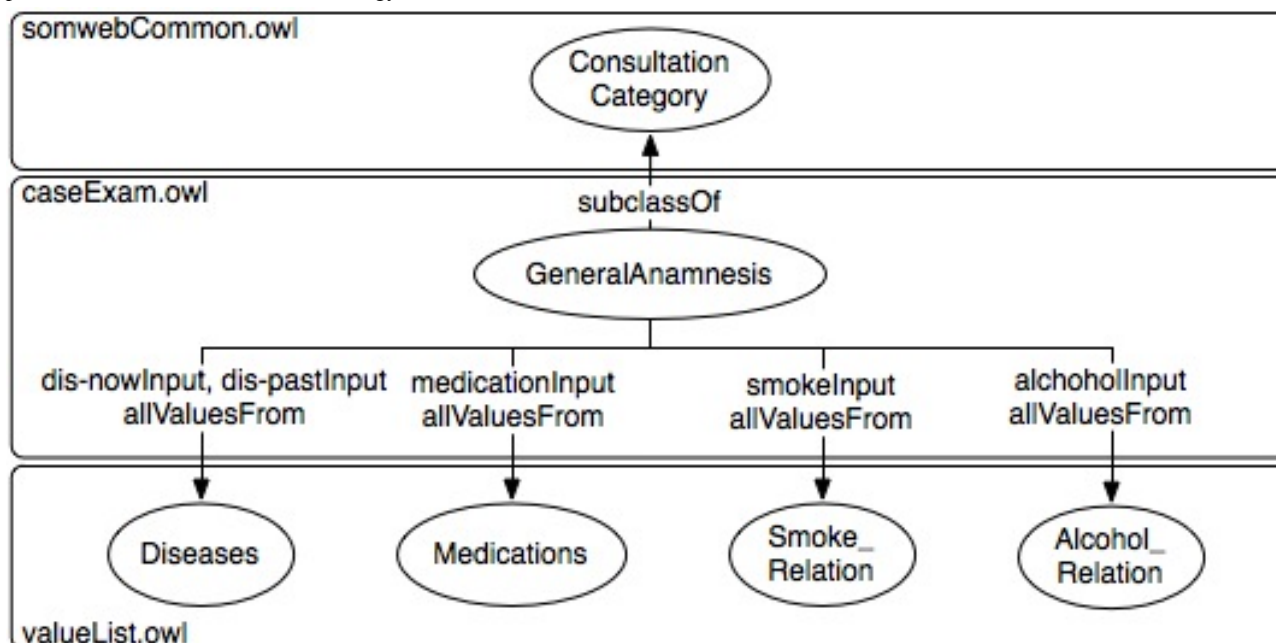
community-defined presentation templates and natural language generation.

Semantic Web Technology Use in SOMWeb

Community aspects, such as users, meetings, cases, and news are modeled using OWL, and community data related to these are represented in RDF. Parts of the user descriptions make use of classes and properties from an external vocabulary called Friend of a Friend. All case data, that is all consultations, are stored in RDF.

Figure 7. An example of a ConsultationCategory, GeneralAnamnesis, showing how OWL allValuesFrom restrictions are used to connect its inputs (properties) to classes of the value list ontology

The form used in entering each kind of consultation is generated from a community-defined template. The templates and associated value lists are represented in OWL (as described in [27]). Templates consist of categories with associated questions (also called inputs). When filling out a form, values for each input may be chosen from a specified class of the value list. Each template is stored in a different OWL file. Additionally, classes and properties common to all templates are defined in a separate OWL file. A template defines categories that can or need to be included in a consultation constructed from that template. For example, ConsultationCategory, a class common to all templates, is subclassed in an individual template by categories such as PatientData and MucosAnamnesis. Inputs are defined in the template, using OWL properties, along with what subclass of ConsultationCategory they are associated with and from what classes in the value list ontology values can be chosen. An input can also have properties with descriptions for when the input should be used and instructions to be shown when filling out the form. All clinical terms in the value list ontology (eg, Allergy) are represented as OWL classes, with their values as individuals (eg, PeanutAllergy). See Figure 7 for an example.

System Architecture

The SOMWeb system is a layered architecture with four main layers: view layer, session layer, model layer, and foundation layer. The view layer consists of Java server Pages using Expression Language constructs, including both custom tags and tags from the Java Standards Tag Library and various Apache struts tag libraries. Cascading Style Sheets are used for styling and layout of content. The components of the session layer deal with the current user session and transforming the application's internal state into the presentation JavaBeans used by the server pages. The model layer handles the application's internal state. This includes persistence classes, which create objects of the corresponding Java classes used by the system from RDF descriptions of users, meetings, cases, and news.

Evaluation of SOMWeb

By May 2008, SOMWeb had 90 registered users located at 48 clinics; 93 added cases had been added and form the basis of a community repository of cases in oral medicine, and 18 meetings had utilized SOMWeb. Eleven users have submitted one case, five users have submitted two to four cases, four users have submitted five to six cases, four users have submitted seven to eight cases, and one user has submitted 19 cases.

Usability

All those interviewed stated that the SOMWeb system has improved the SOMNet collaboration. Several reasons were given: making case entry easier and less time consuming, prompting the supply of more uniform case data, enabling a collected view of a case over time, and providing more structure to SOMNet's activities in general. Some also found that SOMWeb gave a greater sense of presence since it is possible to see in a clearer manner who other members are and who adds cases. Table 1 displays questionnaire responses comparing SOMWeb with the PowerPoint support.

Table 1. Users' experience of SOMWeb's functionality compared to the previous form of collaboration (These questions were answered by the 20 out of the 24 respondents who indicated that they had participated in SOMNet with PowerPoint support. Out of these 20, several did not answer all questions.)

Functionality	Rating Scale	Score
Using the case repository	Better/neutral/worse	14/4/0
Adding cases to the repository	Better/neutral/worse	13/2/0
Viewing old cases	Better/neutral/worse	15/2/0

When the PowerPoint presentations were used in the meetings, the users first went through the slides sequentially and then looked at specific slides as appropriate in the discussion. When using SOMWeb in meetings, users focus more on the images while listening to the presenter and rely on the textual case information for looking up facts as they need them. In SOMWeb, the cases are presented in the order in which they have been entered into the system, but the actual order of presentation is usually based on the preferences of the presenters.

Six of the nine interviewees had added cases. All of them found that it was easier to enter cases with the new system, yet only four found it very easy. The difference between these numbers indicates that there is some variation in opinion regarding case entry. Two respondents were concerned that the value lists had duplicate and misspelled entries, while two other respondents found the lists to be quite thorough and recognized that these will always contain some odd values. One respondent thought it took too much time to fill in the form and mainly used the free-text entry of the form. Another respondent found it difficult to select which data to enter for patients with a complicated clinical situation. Yet another respondent thought that some questions were missing from the form. Some users had trouble finding out how to submit a case for follow-up consultation.

Another identified problem is that images are sometimes loaded slowly when there is heavy system usage during meetings.

System Use

All interviewees use SOMWeb mainly in conjunction with meetings. All of them use the system a few days before the meeting or on the day of the meeting to go through cases and form their own opinion about the case. One person indicated that the personal comments in the system were used to remember these opinions. Another person used these comments to record notes during the meeting.

Though not explicitly asked of all interviewees, five reported that they had logged in to browse previous cases. One of these replied that this had never been done for the previous PowerPoint-based approach. Three interviewees had used the simple free-text search functionality but found that it needed improvement. Two others replied that the search had not been used since they found that the number of cases in the system did not yet warrant a need for searching.

Impact on Chairpersonship and Recording of Meeting Decisions

Included in the SOMWeb system is the possibility for the chairperson to add a meeting consultation to the discussed cases, where the group's recommendations are entered. The idea is that after the meeting, the chairperson goes through any notes taken and adds relevant parts to each case. However, after about a year of use we found that this functionality was underused, partially because of a lack of time for the person chairing all meetings during this year. With SOMWeb also came the functionality of assigning a chairperson for each meeting. In June 2007, it was decided that the chair should rotate, partially because of the problem noted above. Since this decision, meeting preparations are more thorough and notes have been added for most cases (at five out of eight meetings since the start of rotation). For the meetings where notes were not added, reasons were found to be lack of knowledge that this should be done and lack of time. The instructions for the chairperson have been improved to alleviate this.

Impact on Use of External Evidence

In SOMWeb, article references can be added to all cases in a structured manner. This functionality was not included initially, and prior to this, articles were added as part of the chairperson's notes. The news page has also been used to communicate articles of more general relevance. Though it was not part of the interview questions, four respondents indicated that they usually print and read the articles suggested. Only one of these has a research position and thus follows new publications independently of SOMWeb.

Impact on Collaboration Practices

The simple emailing facility of SOMWeb has also lead to more contact between the clinicians outside of meetings. Interviewees have found that this simple procedure saves them time in that they do not have to update their own address list.

When the SOMNet activities started more than 10 years ago, only four clinicians participated in the case discussions. In the beginning, PowerPoint presentations were distributed through email to less than 10 participants, all specialists in oral medicine. At that time, there were no passive members (ie, SOMNet comprised a small group of active clinicians who all participated in the discussions). The breakthrough came when clinical cases were distributed using SOMWeb. With little administrative effort, all members were able to access the website, and during the last 3 years, the number of members has increased tenfold. There is still a nucleus of five to 10 specialists who conduct most of the discussion. The more passive members are more inexperienced clinicians who learn from the main discussions and just occasionally ask questions. Holding more meetings has been suggested, though it has been brought up that each meeting might then get fewer participants. Another interviewee brought up the fact that the meetings feel stressed and that there is not time to discuss each case thoroughly. Dealing with this by limiting the number of cases has been discussed, but there has

been no decision regarding who should decide what should be an adequate number of cases and how to choose between them.

Discussion

Semantic Web technologies have been used for formalizing cases, examinations, and user data. As of May 2008, there were 90 registered users, 93 cases had been added to SOMWeb, forming a community repository of cases, and 18 meetings utilized the system. The introduction of SOMWeb has improved the structure of the meetings and the discussions that occur during the meetings, and a tenfold increase in the number of participants has been observed. Users have been found to submit cases to seek advice on diagnosis or treatment, to show an unusual case, or to create discussion. Identified barriers to submitting cases were lack of time, concern about whether the case was interesting enough, and showing gaps in one's own knowledge. The provision in SOMWeb for assigning different chairpersons changed the collaboration in that responsibility for meeting preparations is now rotated.

Comparison With Prior Work

Web-Based Systems for Clinical Practice and Research

Fearn et al present the Caisis system as a "web-based system for integrating clinical practice and research" [28]. There are several similarities between Caisis and SOMWeb. Both are based on a separation between data entry and data presentation, recognizing that these are in essence two different activities. Both adopt a user-centered approach with active involvement from clinicians. Finally, both Caisis and SOMWeb can be said to be structured around formalized patient histories (ie, cases). However, Caisis lacks SOMWeb's foundation in Semantic Web technologies. A lesson learned from the Caisis project is that "as the system becomes more complex and feature-rich with each iteration, the learning curve becomes higher." This problem is explicitly addressed in SOMWeb by using a "multi-layered" design for the user interface.

Based on Semantic Web technologies, the SWAN application aims at providing Alzheimer disease researchers with "an effective, integrated scientific knowledge infrastructure" [29]. The SWAN ontology and the SWAN information management tool are used for representing the different steps in a scientific discovery process and keeping track of hypotheses, with supporting evidence, research documents, clinical tests, and results in the form of data and publications. As far as we can tell, SWAN uses RDF only, not OWL. In terms of what is represented and handled by the system, SOMWeb and SWAN complement each other, and it would be interesting to try to use the SWAN ontology in the modeling of external evidence and see how it supports a case in SOMWeb.

Vega et al present "a cooperative working environment for sharing clinical experience over the Internet" [30]. Although focusing on image data, the presented solution is very similar to SOMWeb in terms of objectives and in focusing on "clinical sessions," which in purpose and structure correspond to our "meetings." However, the cases presented in clinical sessions are not formalized to the extent our cases are, and Semantic Web technologies are not used. As oral medicine is a discipline that is very much centered on images of the oral mucosa, the addition of the functionality presented by Vega et al for manipulating, annotating, and discussing images in real time to SOMWeb is currently being investigated.

Schleyer et al use an oral cancer center as an example of a biomedical research collaboratory [3]. In contrast to the collaborative work conducted within SOMNet, the functionality used by the researchers in the oral cancer center was more focused on distributed data analysis and preparation of publications than on "conversation over shared data, including, for example, images." As is noted below, this is a shift in focus that we expect to see within oral medicine in the near future. In contrast to our approach, that of Schleyer et al is based on "off-the-shelf tools." Without diminishing the advantages of this approach, it can be interesting to discuss its drawbacks in terms of SOMWeb: the problem of being dependent on adequate IT support is somewhat handled in SOMWeb by minimizing the need for IT and computer science experts by adopting end-user control. Problems associated with "poor interface design," tools not being "well matched to tasks and technical progress," and "how to integrate these tools into routine scientific practice" are explicitly addressed and handled in SOMWeb.

Communities of Practice

Wenger et al [14] suggest the need to design for evolution in supporting CoP. In the case of SOMNet, this is very much the case: they began with a simple technical solution, which has successively become more advanced and adjusted to their work processes. One can argue that it was necessary for the users to get used to the system functionality before they identified the need for new features (compare with [31]).

Inviting different levels of participation is another important principle in supporting CoP, and Wenger et al [14] propose that participants of a CoP can often be divided into core, active, and peripheral groups. This reflects the observation that, while it is hoped that all members participate equally, this is not a realistic expectation since different members participate in a CoP for different reasons. The core group consists of members that take on leadership roles and set the agenda for the group. The active members are regular participants in CoP events and sometimes participate in discussions, but not with the intensity or regularity of the core group. A large portion of the participants often belongs to the last group, which mostly observes interactions between core and active members. Reasons for not participating may be that they do not believe that their observations are valuable enough or that they do not have enough time. Wenger and colleagues [14] hold that these periphery activities are a very important part of CoP. Further, these peripheral members are not as passive as they might seem. They take in what is said and may bring it up in private conversations.

The different levels of member participation are clearly discernable in SOMNet. The core members chair meetings, contribute most cases, and are very involved in the discussions. The group of active users participates in most meetings, sometimes contributes comments and provides some cases. Finally, there is a large group of peripheral members who have not added cases and rarely or never make comments. As was

noted previously, the number of peripheral participants has increased with the introduction of the SOMWeb system, and this has enabled the spread of oral medicine expertise beyond the core and active groups.

A third principle of Wenger et al [14] that can be seen at work in SOMNet is the community rhythm. The most prevalent rhythm is the monthly teleconferences. These affect when cases are entered and when members log in to the system. A system in which members added cases with a request for advice and in which other members could reply whenever would probably not work in this case. This conclusion is supported by the observations made by Moehr et al [31].

Multidisciplinary Medical Team Meetings

A SOMNet meeting can be seen as an instance of a multidisciplinary medical team meeting [32], where the team members meet to review patient cases, establish a diagnosis, and decide on the most appropriate treatment plan for the patient. The processes associated with a multidisciplinary medical team meeting system are pre-meeting activities; case presentation and discussion, including negotiation and reinterpretation of findings; deciding on the diagnosis and treatment; recording of the outcome; and postmeeting activities. As we have shown, a SOMNet meeting contains the same set of processes. It would be interesting to see how this structure could aid in the design of future versions of SOMWeb, adding possibilities for cuing chairpersons and participants in the discussions and securing that decisions being made are supported by relevant external evidence.

Impact on Communication and Collaboration in SOMNet

In oral medicine, there is an ongoing discussion on how the discipline should move from an eminence to an evidence-based approach. The major hindrance to this amendment is the traditional manner of conducting clinical work. There is virtually no support to merge individual proficiencies with external knowledge. This barrier is particularly obvious between academic institutions and care providers serving different public health organizations. In this perspective, SOMWeb serves as an example of an expedient method to harmonize evidence-based knowledge. Apart from probably saving both time and effort [33], it is obvious that less experienced clinicians are learning from both submitting their own cases and from participating in discussions of cases presented by more experienced colleagues, who often practise at an academic institution. The opportunity within SOMWeb to agree on various treatment modalities and to evaluate the outcome of these suggested therapies are cornerstones of the learning process. Most likely, this exchange of case-related information will be followed by a demand for a more structured compilation of data of various disorders related to oral medicine, probably in the form of national registers. This movement is supported by SOMS, which has adopted SOMWeb as the national website for continuing education.

The main difference between SOMWeb and other similar initiatives for distance consultations within oral medicine is that, in latter systems, the clinical information is only shared between the specialist and the general practitioner. No efforts are made to save the data systematically for further use and comparison with similar cases. Furthermore, there is no follow-up of suggested treatment strategies, which will hamper the learning process. SOMWeb also brings in knowledge from external sources (eg, scientific papers). Thus, SOMNet internal experiences will be integrated with best available knowledge to the benefit of a single case, thereby contributing to a more evidence-based oral medicine.

One change that the SOMWeb system has provided is that SOMNet members are now more visible to each other via lists of members and what clinic they work at. Another important change is that the chairpersonship now rotates among core and active members. This has several benefits, such as reducing pressure on the original chairperson, which means that notes about the cases from the meeting are more consistently entered. It also means that more members feel involved in the work of SOMNet and that knowledge of how this work is carried out is spread to more people. Since it amounts to more external evidence, such as article references, being added, those clinicians less experienced in searching and using literature get more such exposure.

Semantic Web Technologies in Practice

We have demonstrated the use of Semantic Web technologies to represent community and case data in an online community, where OWL could be used to address most but not all requirements for our knowledge model.

There are benefits of using formalized knowledge modeling for elucidating key concepts, and OWL has become widely used in this area. In addition, using OWL and RDF has made it easy to update the community model as the need has arisen. However, OWL is still evolving, and best practices have emerged while SOMWeb has been developed. We found a lack of guidance for several design choices and for development of OWL ontologies at different levels of sophistication.

A prospective benefit of using ontologies is the ability to reuse external sources, but we have not able to do this to the expected extent. Partially, this is due to the general lack of available ontologies in OWL. At a more foundational level, one can discuss to what extent ontologies can be readily reused since they are often developed with a certain purpose in mind. Some of the proposed benefits of Semantic Web technologies come from being able to share data with a larger audience. However, in the case of SOMWeb, such data sharing is not advisable given the nature of our data. Thus, we were not able to test the scalability of Semantic Web technologies in distributed systems.

Conclusions

We have shown how an online Semantic Web-based CoP, SOMWeb, can successfully be developed and brought into daily clinical practice. In contrast to most work on CoP in the medical domain, SOMWeb aims at supporting activities related to both clinical practice and research within a distributed medical community, as exemplified by the SOMNet. Based on a firm foundation in knowledge representation and management, where OWL and RDF are used for representing community data and oral medicine knowledge, and on studies of collaboration and

communication within SOMNet, functionality for Web-based distributed meetings has been developed iteratively, in close cooperation with the clinicians.

Studies and analysis of the use of SOMWeb show that it is beneficial for individual clinicians as well as for the SOMNet community. The introduction of SOMWeb has improved the structure of meetings and the discussions that take place, which constitute the core activities of SOMNet. Since the introduction of SOMWeb, there has been a tenfold increase in the number of meeting participants. SOMWeb provides an opportunity for its members to share high quality clinical practice knowledge as well as external evidence related to complex oral medicine cases, thereby contributing to a more evidence-based oral medicine.

As an example of an interdisciplinary team that can successfully address and solve complex research problems within the dental informatics domain [34], SOMWeb is the result of more than 10 years of collaboration between medical practitioners and researchers, computer scientists, and researchers within interaction design. This is probably the main success factor of the reported work. From the start, the composition of the development team included members acting as a "bridge" between the clinicians and the researchers, ensuring that the results of the latter are of real use and are adopted into practice by the former. A distinguishing feature of SOMWeb is the delegation of control of fundamental parts of the system to the end users. This means that the clinicians themselves have been able to adopt the system to their specific needs, requiring little interaction with computer specialists, contributing to the overall acceptance of the system. As an application of Semantic Web technologies, SOMWeb constitutes a sought-for experience report to the Semantic Web research community.

Within CoP, the importance of a champion is stressed. The champion is an authority within the domain in question, the driving force behind the work within the CoP, a precursor within the domain in terms of CoP-related technologies and tools, and the guiding example that others will follow. In the case of SOMWeb, a champion in this sense exists, together with a dedicated group of core users who are prepared to try out new ideas and solutions. In addition, SOMWeb has been designed to be aligned with the rhythm of the collaboration within SOMNet (ie, to use the SOMNet meetings as the basis for SOMWeb).

Future Work

The overall aim of our research is to better understand collaboration and interaction among clinicians in order to improve IT tools that support evidence-based medicine.

In the short term, this translates to (1) continued study of the collaboration and communication within SOMNet and the use of the SOMWeb system; (2) further usage of the Semantic Web-based foundation, by using the domain ontology and reasoning (eg, to inform the browsing of cases) and by adding user and organizational ontologies; (3) adding functionality for real-time annotation of images during meetings; and (4) making the transition to Internet-based telephone services.

In the longer term, since cooperative care and knowledge sharing and dissemination are fundamental parts of evidence-based care in any medical discipline, developing SOMWeb into a general tool that builds online CoPs for other medical disciplines is an interesting prospect.

Conflicts of Interest

None declared.

References

1. Wiecha J, Pollard T. The interdisciplinary eHealth team: chronic care for the future. J Med Internet Res 2004 Sep 3;6(3):e22 [FREE Full text] [Medline: 15471748] [doi: 10.2196/jmir.6.3.e22]
2. Patterson V, Swinfen P, Swinfen R, Azzo E, Taha H, Wootton R. Supporting hospital doctors in the Middle East by email telemedicine: something the industrialized world can do to help. J Med Internet Res 2007 Oct;9(4):e30 [FREE Full text] [Medline: 17951214] [doi: 10.2196/jmir.9.4.e30]
3. Schleyer TKL, Teasley SD, Bhatnagar R. Comparative case study of two biomedical research collaboratories. J Med Internet Res 2005 Oct;7(5):e53 [FREE Full text] [Medline: 16403717] [doi: 10.2196/jmir.7.5.e53]
4. Séror AC. A case analysis of INFOMED: the Cuban national health care telecommunications network and portal. J Med Internet Res 2006 Jan;8(1):e1 [FREE Full text] [Medline: 16585025] [doi: 10.2196/jmir.8.1.e1]
5. Sackett DL, Rosenberg WM, Gray JA, Haynes RB, Richardson WS. Evidence based medicine: what it is and what it isn't. BMJ 1996 Jan 13;312(7023):71-72 [FREE Full text] [Medline: 8555924]
6. Powell J, Buchan I. Electronic health records should support clinical research. J Med Internet Res 2005 Mar;7(1):e4. [Medline: 16403717] [doi: 10.2196/jmir.7.1.e4]

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7. Stefanelli M. The socio-organizational age of artificial intelligence in medicine. Artif Intell Med 2001 Aug;23(1):25-47. [Medline: 11470215] [doi: 10.1016/S0933-3657(01)00074-4]

8. Stefanelli M. Knowledge and process management in health care organizations. Methods Inf Med 2004;43(5):525-535. [Medline: 15702214]

9. Byrne E, Gregory J. Co-constructing local meanings for child health indicators in community-based information systems: the UThukela District Child Survival Project in KwaZulu-Natal. Int J Med Inform 2007 Jun;76(Suppl 1):S78-S88. [Medline: 17015035] [doi: 10.1016/j.ijmedinf.2006.05.018]

10. Leonard KJ, Sittig DF. Improving information technology adoption and implementation through the identification of appropriate benefits: creating IMPROVE-IT. J Med Internet Res 2007 May;9(2):e9 [FREE Full text] [Medline: 17513287]

11. Stefanelli M. Knowledge management to support performance-based medicine. Methods Inf Med 2002;41(1):36-43. [Medline: 11933761]

12. Danaher BG, McKay HG, Seeley JR. The information architecture of behavior change websites. J Med Internet Res 2005 May;7(2):e12 [FREE Full text] [Medline: 15914459] [doi: 10.2196/jmir.7.2.e12]

13. Walther JB, Pingree S, Hawkins RP, Buller DB. Attributes of interactive online health information systems. J Med Internet Res 2005 Jul 1;7(3):e33 [FREE Full text] [Medline: 15998624] [doi: 10.2196/jmir.7.3.e33]

14. Wenger E, McDermott R, Snyder WM. Cultivating Communities of Practice. Boston, MA: Harvard Business School Press; 2002.

15. Pan SL, Leidner DE. Bridging communities of practice with information technology in pursuit of global knowledge sharing. J Strategic Inf Syst 2003 Mar;12(1):71-88. [doi: 10.1016/S0963-8687(02)00023-9]

16. van Baalen P, Bloemhof-Ruwaard J, van Heck E. Knowledge sharing in an emerging network of practice: the role of a knowledge portal. Eur Management J 2005 Jun;23(3):300-314. [doi: 10.1016/j.emj.2005.04.008]

17. Podgorelec V, Pavlic L. Supporting collaboration of medical informatics researchers and teams. In: Proceedings of the 20th IEEE International Symposium on Computer-Based Medical Systems. 2007 Presented at: CBMS '07; June 20-22, 2007; Maribor, Slovenia p. 97-102. [doi: 10.1109/CBMS.2007.102]

18. Gruber TR. A translation approach to portable ontologies. Knowl Acquis 1993;5(2):199-220. [doi: 10.1006/knac.1993.1008]

19. Yu AC. Methods in biomedical ontology. J Biomed Inform 2006 Jun;39(3):252-266. [Medline: 16387553] [doi: 10.1016/j.jbi.2005.11.006]

20. Koch S. Designing clinically useful systems: examples from medicine and dentistry. Adv Dent Res 2003 Dec;17:65-68 [FREE Full text] [Medline: 15126210]

21. Heeks R. Health information systems: failure, success and improvisation. Int J Med Inform 2006 Feb;75(2):125-137. [Medline: 16112893] [doi: 10.1016/j.ijmedinf.2005.07.024]

22. Stoicu-Tivadar L, Stoicu-Tivadar V. Human-computer interaction reflected in the design of user interfaces for general practitioners. Int J Med Inform 2006 Mar;75(3-4):335-342. [Medline: 16188492] [doi: 10.1016/j.ijmedinf.2005.08.005]

23. Jontell M, Mattsson U, Torgersson O. MedView: an instrument for clinical research and education in oral medicine. Oral Surg Oral Med Oral Pathol Oral Radiol Endod 2005 Jan;99(1):55-63. [Medline: 15599349] [doi: 10.1016/j.tripleo.2004.01.009]

24. Zhang J. Human-centered computing in health information systems. Part 1: analysis and design. J Biomed Inform 2005 Feb;38(1):1-3. [Medline: 15694880] [doi: 10.1016/j.jbi.2004.12.002]

25. Johnson CM, Johnson TR, Zhang J. A user-centered framework for redesigning health care interfaces. J Biomed Inform 2005 Feb;38(1):75-87. [Medline: 15694887] [doi: 10.1016/j.jbi.2004.11.005]

26. Brender J. Handbook of Evaluation Methods for Health Informatics. New York: Academic Press; 2006.

27. Gustafsson M, Falkman F. Experiences in modeling clinical examinations in oral medicine using OWL. In: Proceedings of the OWLED 2007 Workshop on OWL: Experiences and Directions. 2007 Presented at: OWLED 2007 Workshop on OWL: Experiences and Directions; June 6-7, 2007; Innsbruck, Austria.

28. Fearn P, Regan K, Sculli F, Fajardo J, Smith B, Alli P. Lessons learned from Caisis: an open source, Web-based system for integrating clinical practice and research. In: Proceedings of the 20th IEEE International Symposium on Computer-Based Medical Systems. 2007 Presented at: CBMS '07; June 20-22, 2007; Maribor, Slovenia p. 633-638. [doi: 10.1109/CBMS.2007.66]

29. Gao Y, Kinoshita J, Wu E, Miller E, Lee R, Seaborne A, et al. SWAN: a distributed knowledge infrastructure for Alzheimer disease. J Web Semant 2006 Sep;4(3):222-228. [doi: 10.1016/j.websem.2006.05.006]

30. Vega JM, Rubio VJ, Espigado P, Asensio J, Viñao M, Esteban E, et al. Radiological clinical telesession: a cooperative working environment for sharing clinical experience over the Internet. Med Inform Internet Med 2006 Jun;31(2):129-141. [Medline: 16777787] [doi: 10.1080/14639230600597820]

31. Moehr JR, Schaafsma J, Anglin C, Pantazi SV, Grimm NA, Anglin S. Success factors for telehealth - a case study. Int J Med Inform 2006 Oct;75(10-11):755-763. [Medline: 16388982] [doi: 10.1016/j.ijmedinf.2005.11.001]

32. Kane B, Luz S. Multidisciplinary medical team meetings: An analysis of collaborative working with special attention to timing and teleconferencing. Comput Support Coop Work 2006 Dec;15(5-6):501-535. [Medline: 17567904] [doi: 10.1007/s10606-006-9035-y]

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33.   Schleyer T, Spallek H. An evaluation of five dental Internet portals. J Am Dent Assoc 2002 Feb;133(2):204-212 [FREE Full text] [Medline: 11868839]
34.   Schleyer T, Spallek H. Dental informatics. A cornerstone of dental practice. J Am Dent Assoc 2001 May;132(5):605-613 [FREE Full text] [Medline: 11367964]

Abbreviations

API: application programming interface
CoP: community of practice
CSCW: computer-supported cooperative work
HTML: HyperText Markup Language
IT: information technology
OWL: Web Ontology Language
RDF: Resource Description Framework
SOMS: Swedish Oral Medicine Society
SOMNet: Swedish Oral Medicine Network

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<u>Original Paper</u>

Facebook for Scientists: Requirements and Services for Optimizing How Scientific Collaborations Are Established

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Abstract

Background: As biomedical research projects become increasingly interdisciplinary and complex, collaboration with appropriate individuals, teams, and institutions becomes ever more crucial to project success. While social networks are extremely important in determining how scientific collaborations are formed, social networking technologies have not yet been studied as a tool to help form scientific collaborations. Many currently emerging expertise locating systems include social networking technologies, but it is unclear whether they make the process of finding collaborators more efficient and effective.

Objective: This study was conducted to answer the following questions: (1) Which requirements should systems for finding collaborators in biomedical science fulfill? and (2) Which information technology services can address these requirements?

Methods: The background research phase encompassed a thorough review of the literature, affinity diagramming, contextual inquiry, and semistructured interviews. This phase yielded five themes suggestive of requirements for systems to support the formation of collaborations. In the next phase, the generative phase, we brainstormed and selected design ideas for formal concept validation with end users. Then, three related, well-validated ideas were selected for implementation and evaluation in a prototype.

Results: Five main themes of systems requirements emerged: (1) beyond expertise, successful collaborations require compatibility with respect to personality, work style, productivity, and many other factors (compatibility); (2) finding appropriate collaborators requires the ability to effectively search in domains other than your own using information that is comprehensive and descriptive (communication); (3) social networks are important for finding potential collaborators, assessing their suitability and compatibility, and establishing contact with them (intermediation); (4) information profiles must be complete, correct, up-to-date, and comprehensive and allow fine-grained control over access to information by different audiences (information quality and access); (5) keeping online profiles up-to-date should require little or no effort and be integrated into the scientist's existing workflow (motivation). Based on the requirements, 16 design ideas underwent formal validation with end users. Of those, three were chosen to be implemented and evaluated in a system prototype, "Digital|Vita": maintaining, formatting, and semi-automated updating of biographical information; searching for experts; and building and maintaining the social network and managing document flow.

Conclusions: In addition to quantitative and factual information about potential collaborators, social connectedness, personal and professional compatibility, and power differentials also influence whether collaborations are formed. Current systems only partially model these requirements. Services in Digital|Vita combine an existing workflow, maintaining and formatting biographical information, with collaboration-searching functions in a novel way. Several barriers to the adoption of systems such as Digital|Vita exist, such as potential adoption asymmetries between junior and senior researchers and the tension between public and private information. Developers and researchers may consider one or more of the services described in this paper for implementation in their own expertise locating systems.

Introduction

Social networking technologies have become one of the latest "killer applications" on the Internet, with some sites such as MySpace and Facebook amassing large numbers of users in a very short period of time [1]. While those sites initially focused on younger demographics such as teenagers and college students, they are now encompassing rapidly growing segments of adult and/or professional users. Professionals are beginning to employ such systems for, among other things, extending their professional networks (ie, by learning about colleagues of colleagues), locating experts to solve specific problems, and finding collaborators.

Social networking approaches have the potential to help scientists find appropriate collaborators more quickly and efficiently than is currently the case. Over the past several decades, science has become significantly more collaborative, both generally [2,3], as well as in biomedicine [4]. The increasing frequency with which the terms *interdisciplinarity* and *multidisciplinarity* appear in the literature [5] illustrates this strong trend toward collaboration. As a result, collaboration with the right individuals, teams, and institutions is becoming ever more crucial to project success. New programmatic initiatives such as the Roadmap [6,7] and the Clinical and Translational Science Award (CTSA) [8] programs of the National Institutes of Health (NIH) and the Janelia Farm Research Campus of Howard Hughes Medical Institute [9] in the United States demonstrate that funding agencies and research organizations are not just passively observing this trend but are actively encouraging it.

Currently, most researchers use one of two primary methods to find new collaborators [10]. One approach is to turn to colleagues in their existing social network [10-12]. Colleagues, especially senior ones or those "in the know," are often able to quickly identify promising candidates for collaboration, to provide input on their potential compatibility and credibility, and to make an introduction. The second method is to search for potential collaborators through published works [10], done most commonly in online databases such as PubMed and Google Scholar. Information from these databases helps the collaboration seeker gauge the potential collaborator's competence, credibility, and interest, but it provides no support for gaining access. Soliciting collaboration may begin with "cold calling" if no connection through a third person is possible.

A third method for finding collaborators is to use databases of researchers partially or exclusively designed for the purpose. Knowledge management systems of this type, which include "expertise locating systems" [13], "knowledge communities" [14,15], and "communities of practice" [16,17], all provide, to varying degrees, support for finding experts and, by extension, potential collaborators. In the literature, the functions and definitions of these types of systems are not cleanly separated. It appears that expertise locating systems (also called expertise locator systems) as their core function most directly focus on the ability to find individuals knowledgeable in a particular problem/domain.

The computer-supported cooperative work (CSCW) literature contains numerous examples of systems designed to connect people with each other to solve specific problems [13,18-23]. The Expertise Recommender [13] is a recommendation system to help company workers locate persons best qualified to assist with a specific problem. The Zephyr Help Instance [18] and ReachOut [19] are examples of simple lightweight collaborative systems to tap the expertise within a company. Email is sometimes used to exploit weak and latent ties within a professional community [24]. Most of these systems serve to help a person solve a specific problem at a particular point in time. Consequently, one of their most important functions is to help identify the person who is best equipped to assist with solving the problem in a specified time frame.

In this study, we are focusing on the much bigger challenge of establishing the long-term collaborations typical in biomedical science. In this case, not only are researchers looking for the most qualified expert, but they also will most likely enter into a long-term relationship. Evaluating an individual's promise for such a long-term relationship requires information, engagement, and effort much beyond what is needed for finding an expert for singular (or even episodic) problem solving. A thorough literature search located only one report of a system [21] specifically designed to help scientists meet this challenge.

In contrast to the dearth of reports in the literature, electronic systems purporting to make it easier to help scientists find collaborators abound. Similar to social networking sites such as Facebook, such systems endeavor to help individuals make connections to others that are not likely to be made in an off-line context [25,26]. Among the more established systems is the Community of Science (COS), which provides a "database of detailed, first-person profiles of more than 480,000 R&D

professionals and scholars" [27]. Another system, the Faculty Research Interest Project (FRIP) [21], is in use at the University of Pittsburgh and currently indexes 1926 research faculty of the six schools comprising the Health Sciences Center. Another system, ExpertFinder [20], has been designed to help employees of The MITRE Corporation locate experts within the company. LinkedIn, Innocentive, Index Copernicus Scientists, Research Crossroads, and BiomedExperts are some of the more recent commercial offerings that advertise large directories of professionals/scientists. A thorough search for literature evaluating how well these systems facilitate the initiation of collaborations yielded no results. While these systems provide significant value to individuals looking for someone with specific expertise, anecdotal evidence suggests that they currently do not play a significant role in helping researchers establish collaborations.

However, there are good reasons to suspect that expertise locating systems could help scientists find the most appropriate collaborator(s) more quickly and efficiently than is currently the case [26]. General trends in scientific research are compelling scientists to become more collaborative than they already are. As academic/research institutions extend the scale and scope of their research portfolio and, in the process, the numbers of their research faculty, more individuals are available for collaboration, either locally or remotely. At the same time, online databases, such as Google and PubMed, make locating collaborators easier. The number of potential collaborators is also increased by modern communication and collaborative technologies—many remote collaborations that would have once been considered impractical have now become feasible. The result is an "embarrassment of riches" for scientists seeking collaborators. Unfortunately, with this ever-expanding pool of potential collaborators, the task of selecting optimal collaborators is becoming more onerous and requires more effort from researchers, simply because there may be many more good options to choose from than previously possible. Studies have shown that when faced with this type of social overload, individuals are more likely to adopt competitive or withdrawal strategies and thus tend to be less cooperative [28]. Systems that help scientists "quality filter" the realm of possibilities for the most promising potential collaborators could help alleviate this social overload [29] and achieve more appropriate collaboration decisions at lower cost to the collaboration seeker.

The confluence of the trends of increasing scientific collaboration, the emergence of social networking as a powerful mediator of social interaction, and the growing availability of information about scientists and their work presents a significant opportunity to investigate whether expertise locating systems can make the process of finding collaborators more effective and efficient. Current systems are relatively new and have an uncertain track record. One immediate question that occurs is whether those systems are responsive to the requirements of scientists seeking collaborators. In answer to this question, the main goal of this study was to develop preliminary, generalizable requirements for expertise locating systems for biomedical scientists. Its second goal was to design a set of services responsive to these requirements, implement them in

a prototype system, and formatively evaluate them with representative end users.

The main focus of this paper is to describe services and functions useful for expertise locating systems in general, not their implementation in a specific system. This study has been conducted as part of the University of Pittsburgh's Clinical and Translational Science Institute in response to the core challenge to accelerate scientific discovery and the application of its results. As the other 23 current CTSA awardees in the United States are pursuing the same goal, our results are highly significant in that context. In addition, we hope that scientists and developers of expertise locating systems consider our results in the context of their own projects, potentially adopt/implement them, and conceptualize and design additional services as necessary.

Methods

This project proceeded in two phases: the background research phase and the generative phase. While the background research phase of the project emphasized discovering as much as possible about the relevant problem domain, the generative phase was intended to develop as many viable solutions as possible and then to choose one or more approaches to implement in a prototype. The project team included two faculty from the Center for Dental Informatics (TS and HS), one faculty from the Katz Graduate School of Business (BB) at the University of Pittsburgh, and two faculty (Susan Fussell and Brad Myers) and five senior masters students (SS, DW, LP, PR, and GM) from the Human-Computer Interaction Institute at Carnegie Mellon University. The project took place from January to August 2007. We describe the two main project phases briefly below.

Background Research Phase

We began the background research phase with a systematic literature review on relevant topics from the computer-mediated communication, social network theory, and computer-supported cooperative work literature. Keywords included "expertise locating systems," "expertise management systems," "knowledge communities," "knowledge management," "knowledge management systems," "communities of practice," and "virtual communities." We searched Medline, the ISI Web of Science, the ACM Portal, and the IEEE Digital Library (all available years). From this material, we generated an affinity diagram [30] of issues and questions involved in the initiation of collaboration. We then performed contextual inquiries (CI) [31] with 10 researchers at Carnegie Mellon University and the University of Pittsburgh from a range of disciplines and levels of seniority. Since we could not directly observe researchers forming collaborations, the contextual inquiry was based on retrospective accounts. We also used a technique called directed storytelling in which we presented hypothetical situations to the interviewees and had them walk us through what they would do in each given situation. For each CI session, we generated workflow, sequence, and cultural models [31].

Table 1. Researcher affiliation, gender, seniority, collaborator count, and perceived collaborative load

School	Gender	Seniority	Number of Collaborators	Perceived Collaborative Load
Medicine	M	Junior	3-4	too few
Medicine	F	Junior	4	too few
Medicine	M	Senior	4	too few
Medicine	F	Junior	7	too few
Dental	M	Junior	7	too few
Rehabilitation	M	Senior	9	too few
Public Health	F	Junior	10	too few
Pharmacy	F	Junior	25	too few
Pharmacy	M	Junior	6	just right
Medicine	M	Senior	6-8	just right
Medicine	F	Junior	8	just right
Nursing	F	Junior	8	just right
Rehabilitation	M	Senior	8	just right
Pharmacy	M	Junior	9	just right
Pharmacy	M	Senior	9	just right
Medicine	M	Junior	10	just right
Medicine	M	Senior	10	just right
Dental	M	Senior	15	just right
Nursing	F	Junior	20	just right
Medicine	F	Junior	20	just right
Public Health	M	Senior	30	just right
Rehabilitation	M	Junior	30-50	just right
Public Health	M	Senior	16-20	too many
Medicine	M	Senior	24	too many
Public Health	F	Senior	40	too many
Public Health	M	Senior	7	n/a
Dental	M	Senior	15	n/a

In a parallel study, we conducted semistructured interviews with 27 scientists at the University of Pittsburgh (see Table 1). The interviews contained 10 main questions and focused on current and previous collaborations, finding collaborators, solving problems in research, and information needs and information resource use of participants. The interview study was conceived as a pilot study since few formal investigations of these topics have been reported in the literature [10]. The interviewers conducted the interviews individually and transcribed their notes shortly thereafter.

We analyzed the semistructured interviews using grounded theory [32], an approach in which the interviewer and one other researcher annotated each transcript independently. Annotations were formulated as themes from which the annotators induced initial hypotheses about the attitudes, motivation, and behavior of the interviewees. A third researcher summarized all annotations and themes, as well as whether they supported or refuted the particular hypothesis or hypotheses they related to.

We modeled three of the semistructured interviews in accordance with the CI method described above and added the resulting workflow, sequence, and cultural models to the 10 sets of models developed during the CI phase. We did this in order to increase the variety of observations and add insights that may have been articulated during the interviews but not during the CI sessions. Subsequently, we consolidated the data into single flow, sequence, and cultural models. The flow model provided a good view of actors and their roles and the flow of information among them. The cultural model identified the cultural aspects that have a strong influence on whether and how collaborations are formed.

We then derived a detailed set of requirements from the consolidated models and the results of the interviews and categorized them into five main themes: compatibility, communication, intermediation, information quality and access, and motivation. These themes served as the basis for developing the design ideas during the generative phase, which we describe next.

Generative Phase

The generative phase began with brainstorming design ideas for systems to help facilitate the establishment of collaborations in light of the system requirements we had formulated. Two initial brainstorming sessions resulted in a total of over 40 ideas. The ideas included semiautomatic updating of online profiles; locating collaborators through colleagues or matching research interests in published papers; utilizing online journal clubs, online video presentations, and live question-and-answer sessions; social tagging of research papers; facilitating directed social contact through methods such as ride sharing and hobby groups; and creating systems to support matchmaking through "social hubs," such as department chairs. Several of the ideas drew on functions available in the Web 2.0 and ubiquitous/mobile computing technology spaces.

Sixteen of the 40 ideas generated during the brainstorming phase were selected for formal concept validation. During this phase, we evaluated the design concepts with nine researchers at the University of Pittsburgh Health Science Campus. The participants represented scientists at the junior, senior, and executive levels with varying research foci (basic, clinical, and translational) at several schools. We presented each design idea as a real-life scenario to the participant and solicited feedback on its functionality and usefulness. Thus, we used the viewpoint of the end user as a central guiding principle for shaping our designs, an approach crucial to the development of user-centered applications [31]. The scenarios employed "personae," which are archetypal representations of individuals that represent either the participant or individuals they would encounter when interacting with the system. For instance, "Carlos" was characterized as an inexperienced junior researcher at the School of Pharmacy in the early stages of his career. He had few contacts and was willing to be less selective about collaborative projects in order to gain experience and expand his network. "Bernice," on the other hand, was a well-known biomedical researcher who demanded a rigorous work style and could afford

to discontinue collaborations she felt were fruitless. The personae brought life to the scenarios and allowed participants to act and react naturally with regard to the proposed ideas. A facilitator presented the scenarios and guided user feedback through scenario-specific questions. At least one other observer was present to record notes. The sessions were audio-recorded as a reference for analysis.

For each design idea, the individual ratings of the researchers were combined into a summary score that ranged from 1 (not needed) to 4 (very much needed). At the same time, the project team rated the feasibility of implementing each idea on a scale from 1 (low) to 3 (high). The feasibility rating integrated judgments about how difficult it would be to implement each idea based on technical, environmental, and cultural considerations.

Based on the feedback from the concept validation sessions, we selected three related ideas for implementation and evaluation in a prototype. We implemented the design first as a wire frame, then as a high fidelity prototype. We performed think-aloud evaluations with four scientists using three use cases. The use cases described common scenarios that we asked participants to complete using the Digital|Vita prototype. Two observers kept notes on the interaction of each participant with the system, focusing on functions that were found to be either problematic or useful. The development team then brainstormed system improvements and implemented them to the highest degree possible. The high-fidelity prototype was used to produce a video about the system, which served as a way to solicit input from senior decision makers and external reviewers.

The studies conducted as part of the background research phase and generative phase were approved by the University of Pittsburgh Institutional Review Board (IRB approval numbers: 0612065 and PRO07050299).

Results

The background literature review, affinity diagramming, contextual inquiry, and semistructured interviews yielded five themes of requirements for systems to support the formation of collaborations. The themes are compatibility, communication, intermediation, information quality and access, and motivation. We briefly describe the themes below.

Themes for System Requirements

Compatibility

Beyond expertise, successful collaborations require compatibility with respect to personality, work style, productivity, and many other factors [10,33]. Although exceptions exist, the majority of researchers interviewed saw compatibility of personality and work style as a prerequisite to collaboration. Therefore, more than a simple overlap of interests is needed to create a successful collaboration. The researchers we interviewed indicated that they would not trust an impersonal recommendation or suggestion made by a system about potential compatibility, putting them somewhat at odds with what users of dating sites and Facebook are apparently willing to do [34,35]. If researchers cannot assess compatibility with potential

collaborators personally, they primarily appear to trust personal recommendations from colleagues. For this reason, expertise locating systems should show social connections between the collaboration seeker and potential collaborators.

Communication

Finding appropriate collaborators requires the ability to effectively search in domains other than your own using information that is comprehensive and descriptive [29,36]. However, researchers are often unlikely to be very familiar with the terminology they need in order to find a specific area of expertise in another domain [29]. One way that researchers currently solve this problem is by asking boundary-spanning colleagues and friends familiar with both realms about whom they should contact for help with solving a particular research problem. While the system should provide researchers with the ability to search directly for expertise, it should also make explicit who in their own professional network may be able to guide them effectively to other experts for resolving questions in different disciplines, organizational units, or research groups. A second requirement for communication is to broaden the ability to search for experts using more information than just publication databases such as Medline or Google Scholar. Those databases typically describe the knowledge and expertise of a researcher in less detail and less comprehensively than a complete curriculum vitae (CV). The CV can support a richer form of evaluation because it provides a more complete picture of the individual's research-related activities, such as grants, grant reviews, patents, editorships, and positions in associations. Expertise locating systems should therefore not only allow the user to search a potential collaborator's publications, but also their research interests, grant submissions, and biographical information.

Intermediation

Social networks are very important for finding potential collaborators, assessing their suitability and compatibility, and establishing contact with them. Established researchers often use existing connections with colleagues as their primary resource for locating new collaborators. However, junior researchers with few or no contacts within the desired field may have significant difficulty initiating collaborations [26]. Researchers are more likely to contact a friend or colleague who they think will know an expert than to cold-call the author of a relevant research paper [24]. Advantages of personal contact include a higher likelihood of compatibility between parties, increased chances of a timely response (which is an issue when there is a status differential), and a less intimidating (and potentially face-saving) method of contacting a new party. Websites such as Facebook and LinkedIn circumvent cold-calling by integrating recommendation services and allowing users to see friends of friends. In this way, users' networks are actually expanded to include their friends' networks in addition to their own. The tendency to use friends/colleagues as intermediaries strongly supports the power and influence of existing social networks and suggests that a successful collaboration-networking site will need to leverage this construct for both identification and access [11,12]. Eysenbach [Eysenbach Medicine 2.0 Editorial, this issue]

suggests the new scholarly term "apomediation" for the function of the intermediary, emphasizing the positive guidance toward high-quality resources (in this case, collaborators).

### *Information Quality and Access*

Information profiles must be complete, correct, up-to-date, and comprehensive and allow fine-grained control over access to information by different audiences. Missing, incorrect, and out-of-date information and poor indexing (for instance, through the use of nonstandard vocabularies) of information profiles [15,20,29,37] make it difficult for a collaboration seeker to obtain the information necessary to assess the suitability and appropriateness of a prospective collaborator. Several commercial services, such as the Community of Science, rely on the user to keep their profile up-to-date and correct at all times. Others generate a "preliminary" profile for scientists from public sources, such as PubMed, Computer Retrieval of Information on Scientific Projects (CRISP), and the USPTO database, which the individual must correct and complete in order to generate a comprehensive, up-to-date profile. Several researchers we interviewed indicated that they had public online profiles but that they did not spend much time keeping them current. Given the many factors that collaboration seekers take into account when evaluating potential collaborations, information profiles should be as complete, correct, and up-to-date as possible [26]. In addition, some researchers indicated that given a choice, they would be selective about what information they would consider making public about themselves. For instance, interviewees seemed much more willing to disclose current ideas to collaborators from within their institutions than to those from competing institutions.

Motivation

Keeping online profiles up-to-date should require little or no effort and be integrated into the scientist's existing workflow. In order to provide relevant and up-to-date information to colleagues, researchers must have an incentive to supply the information and keep it current. For example, our study participants regularly invested time updating information in their biographical and professional documents, such as their CV, biosketches for grants, and faculty evaluation forms. They were highly motivated to do so because these documents must be up-to-date in order to obtain grant funding, provide background information when invited to lecture or consult, and participate in university evaluations such as promotion and/or tenure decisions. There is no such motivation to update online profiles. In addition, our contextual inquiries showed that a major problem with the existing workflow is that researchers need to reformat and update the same information in multiple documents. We recognized this as an opportunity to draw researchers into using an online system. If it were possible to streamline the process by synchronizing information in multiple documents, the system would provide an incentive to keep information updated. Therefore, before a database of personal researcher profiles can be used as a tool to initiate collaboration, it must to be adopted as a repository of biographical and research-related information by a wide range of researchers. This "critical mass" problem is one of the classic challenges to the adoption of CSCW systems [38].

Figure 1. Results of the concept validation phase for 16 design ideas using nine scientist participants; need rating: 1 (low) to 4 (high); feasibility rating: 1 (low) to 3 (high)
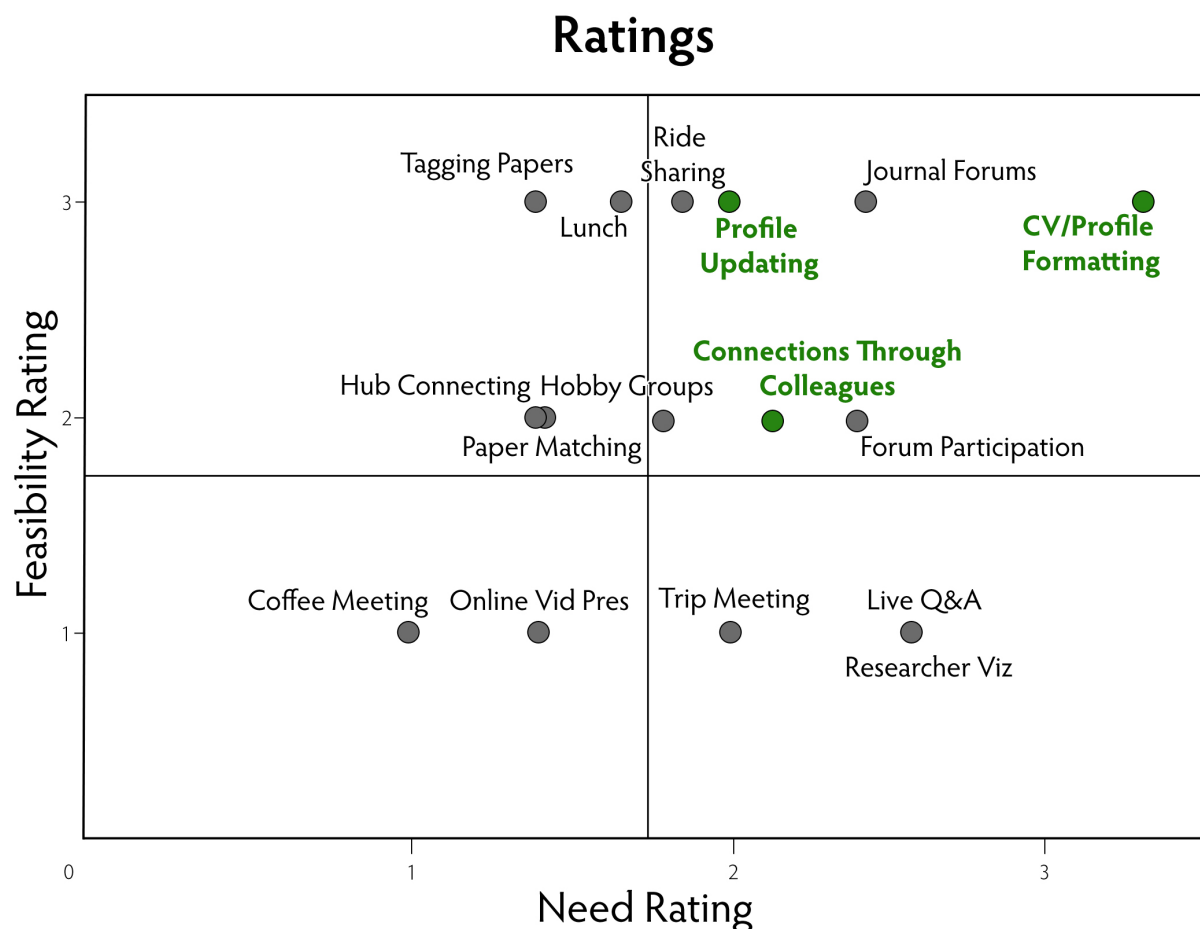
Services for Optimizing How Scientific Collaborations Are Established

As described in the Methods section, the research team generated a large number of ideas for one or more systems to support researchers in locating collaborators. Figure 1 shows the results of the concept validation phase for the 16 design ideas. It is important to note that there is not a 1:1 correspondence between the requirement themes and application ideas. Rather, the different application ideas are responsive to one or more requirement themes to different degrees. In selecting the ideas to be implemented, we aimed to respond to the requirements as best as possible within the context of a software application. The combination of three highly validated ideas, Profile Updating, CV/Profile Formatting, and Connections through Colleagues, appeared to satisfy our constraints most closely and were chosen to be implemented in a prototype system which we dubbed "Digital|Vita." The three main sets of services implemented in Digital|Vita are the following:

1. Maintaining, formatting, and semiautomated updating of biographical information: This set of services allows users to maintain biographical information and output it to several standard formats.

2. Searching for experts: These services provide capabilities for searching for potential collaborators using a range of search criteria and allow searchers to exploit the social network represented in Digital|Vita in the process.

3. Building and maintaining the social network and managing document flow: These services allow users to build a network of social connections, group colleagues into teams, and manage the flow of biographical documents within their teams.

The following sections briefly describe these sets of services.

Maintaining, Formatting, and Semiautomated Updating of Biographical Information

This service is provided by the My Information (see Figure 2) data management function in DigitalVita, which stores biographical information about a user in a comprehensive and detailed manner. Information typically found in CVs, such as education, academic appointments, grants, and publications, can be entered and edited by the user. The items making up each collection, such as single publications, are stored as separate records and logically divided into fields in the database, enabling fine-grained information extraction and display.

Figure 2. The My Information component in Digital|Vita allows the user to enter and update biographical information through manual or semiautomated processes
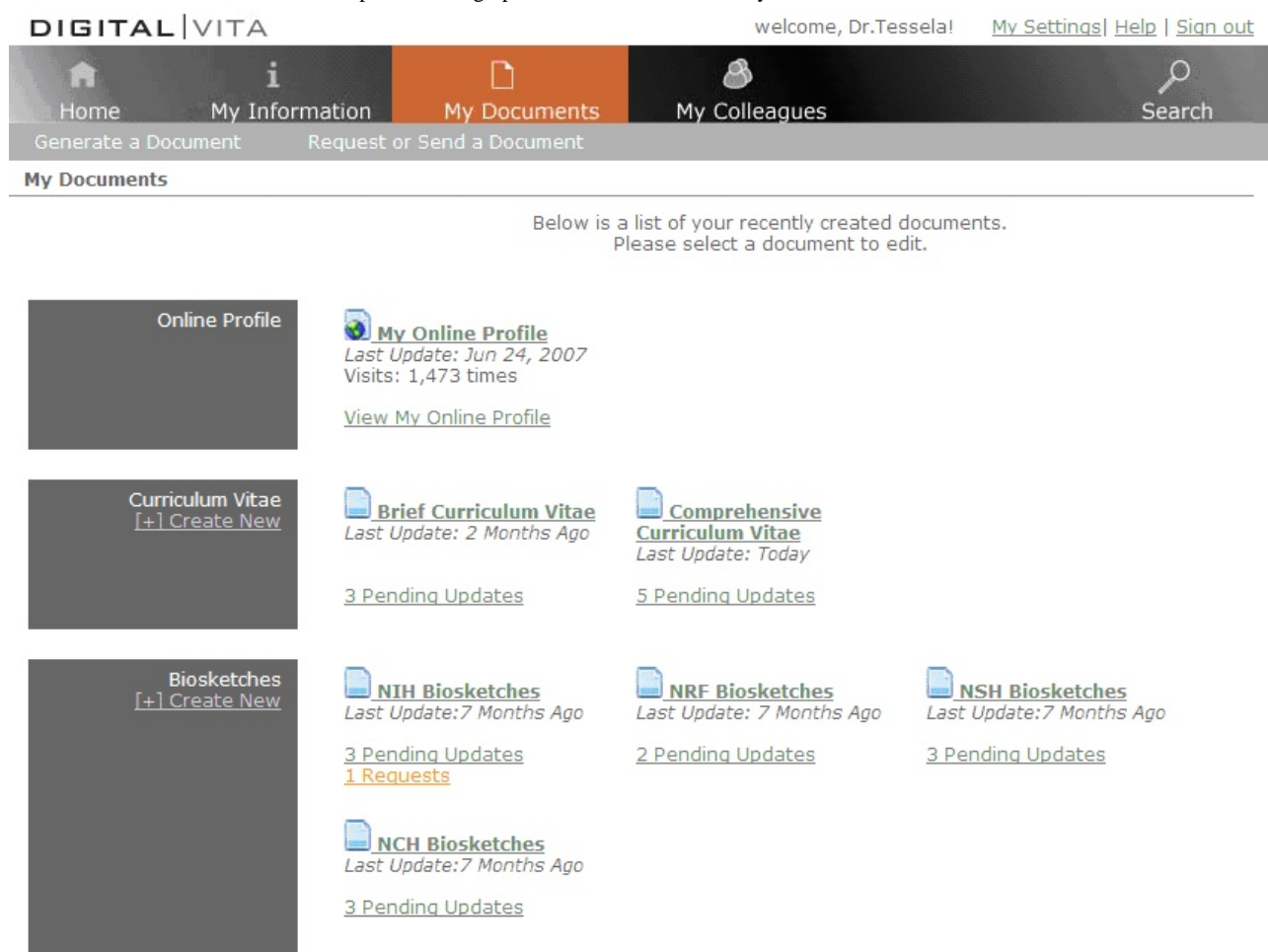

Three services in My Information allow the user to enter and update biographical information:

1. Importing information from existing sources: The primary method for populating biographical information is extraction from existing sources such as the National Library of Medicine's Medline and the National Institutes of Health's CRISP databases. A similar approach to retrieving and aggregating data from existing sources is being used in many other systems [13,20-23]. In Digital|Vita, records from these sources are pre-matched (for instance, through a name search) to the user, and the user simply confirms which records pertain to them. (This approach is used by the Faculty Research Interests Project (FRIP) [21] system currently in use at the University of Pittsburgh. When Digital|Vita is implemented at the University of Pittsburgh,

publications will be imported from the existing FRIP database.)

2. Propagating information through social networks: A second mechanism for acquiring biographical information is the semiautomated synchronization of updates made by colleagues in Digital|Vita. The process is semiautomated because all affected scientists are automatically notified about updated information, but each of them has to manually approve the update for inclusion in their own information. For instance, when Digital|Vita users manually enter a paper, they have the option of selecting coauthors from within the Digital|Vita system. When an entry is saved, Digital|Vita automatically propagates this update to the coauthors and displays it on each user's Digital|Vita home page (see Figure 2). The coauthors can then confirm or reject the update for their own personal profile.

3. Manually entering and updating information: The third mechanism for entering and updating information is manual entry. This is appropriate for data for which existing sources are neither available nor accessible. Examples of such data include professional appointments, degrees, and publications indexed in services that do not allow automated retrieval.

Figure 3. The My Documents component provides functions to output biographical information to several standard formats, customize information content, archive old versions, and include updates to biographical information selectively

While My Information allows the user to input and manage their biographical information, the My Documents function helps the user produce and archive several forms of output from that data. My Documents includes three services:

1. Output to several standard formats: The current design of Digital|Vita provides for several standard output formats for biographical information such as a university-specific CV, a brief CV, and NIH and NSF biosketches. Users can choose the desired output format, generate the new document, and edit it according to their preferences.

2. Customization and versioning: The ability to easily customize document content was deemed essential for the researchers we interviewed because they typically adapt biographical documents for specific grant applications, even if the format required for each is the same. With this service, users can customize documents with a simple checkbox approach—if an item is checked, it is included in the specific document. My Documents also supports versioning so that older versions of a specific document are available on demand.

3. Selective updating: The system makes it explicit when the existing version of a document does not include recently updated information (see Figure 3) in order to allow the user to make an informed choice about including or excluding such updates. When the user customizes documents with information that is not contained in the My Information database, Digital|Vita allows the user to back-propagate the information to My Information. Thus, users do not have to interrupt their current workflow in order to make updates to My Information.

As the user edits a specific document, the system displays the length of the document in pages in order to allow the user to observe page limits. In addition, the user can preview the printed version of the document; send it to colleagues in their professional network and recipients through email; and save the document in predetermined file formats.

Searching for Experts

Our background research indicated that researchers consider a variety of factors when choosing potential collaborators. For many, searching Medline and Google Scholar is only the first step in acquiring several types of information about their colleagues. The purpose of the My Information section in Digital|Vita is to store rich and comprehensive profiles of

researchers in the database and make them available for flexible and powerful searching by others.

1. Simple and advanced search of profiles: The first step in finding an expert within Digital|Vita is to allow users to query profiles flexibly. While the simple search in Digital|Vita only offers the capability to query profiles using keywords, the advanced search adds institution, department, location (for institutions with multiple campuses), publication activity, and relevance. (Relevance is a score indicating the level of expertise of the "hit" regarding the desired research topic.) Search results return key information about each hit (see Figure 4). They include academic affiliation, research interests, publications, and number of citations. Users can sort the search results and compare the appropriateness of potential collaborators. A potential trade-off of this design results from the fact that status, seniority, and relative experience of a person are now explicitly communicated. This could affect the decisions collaboration seekers make because a well-published and experienced researcher is now clearly identifiable as compared to a less published, less experienced researcher. Making these distinctions highly visible may potentially reduce the opportunities junior researchers are offered. On the other hand, it may allow the searcher to target a collaborator's level of experience and expertise more directly. When users have identified one or more promising candidates for collaboration, they can access detailed profiles. Researchers' profile pages contain information they have approved for inclusion by managing the My Profile section of their Digital|Vita. Thus, researchers have relatively granular control over which information is published about them. Typically, the profile page displays detailed information about their background, research interests, and publications (with links to PubMed for abstracts and, in some cases, full-text articles).

2. Exploiting the social network to search: The search results page also displays connections through colleagues (identified by an icon symbolizing a social network, see icon next to "Wendy Roberts" in Figure 4). The icon shows two nodes if the individual is a colleague who belongs to the user's social network and three nodes if the individual is a colleague of a colleague. This design paradigm resembles the functionality of sites such as Facebook and LinkedIn. Users may elect to search only in their extended network (ie, among individuals who are in the social network of their colleagues). Junior researchers may find this feature helpful to avoid having to cold-call potential collaborators. The Digital|Vita design currently does not provide a mechanism for asking a colleague for an introduction electronically, as other systems do.

Figure 4. A sample search results screen in Digital|Vita shows brief profiles of potential collaborators

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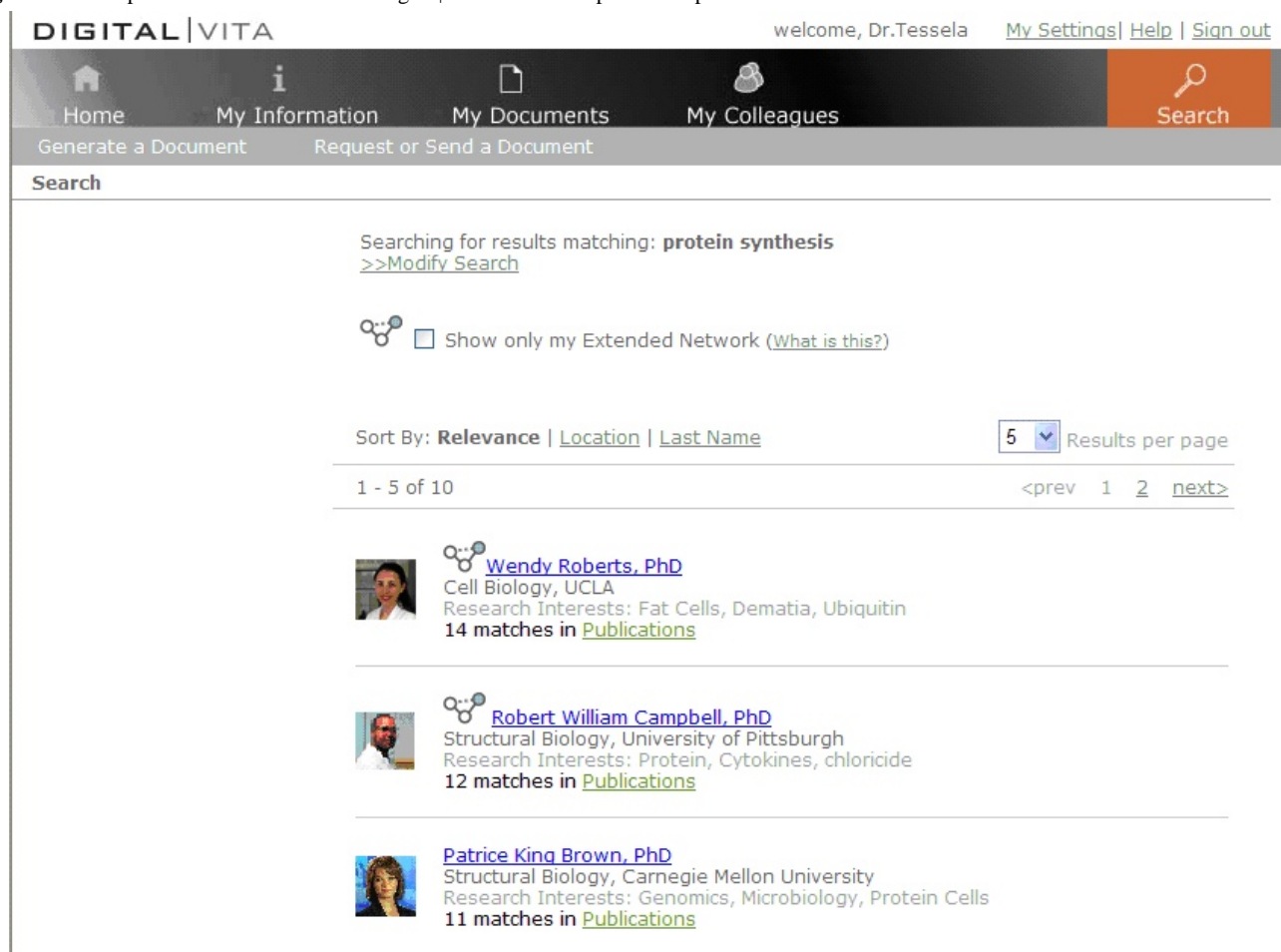
Building and Maintaining the Social Network and Managing Document Flow

This service is managed in the My Colleagues section of Digital|Vita. It is intended for researchers to keep track of their collaborators, colleagues within their department, and general professional network of colleagues within Digital|Vita. It is the area in the system where users build the social network that they are able to exploit when they search for collaborators (see above) and where they manage document flow between themselves and their research teams.

1. Creating links to colleagues: The value of social networks for recommending collaborators has been discussed earlier [39-41]. An obvious hurdle to establishing a social network is that there are few information sources from which data can be drawn to populate it directly. Nonetheless, in order to reduce the work for users, Digital|Vita generates suggestions for individuals to be included in a user's social network by matching coauthors on papers and collaborators on grants with existing researchers in Digital|Vita. Users can then decide individually whether to include the suggested individuals in their social network. However, coauthorship and collaboration on grants are typically no more than partial indicators of collaboration [3]. Therefore, Digital|Vita users can ask anyone in the system to become their colleague. In this case, the system sends an electronic invitation, which the recipient either can accept or reject. In case of rejection, the recipient can opt to provide a reason. The requester is then notified about the recipient's decision. One design alternative that was considered was not to notify the requester about the recipient's decision. This alternative would provide a way to save face for both parties [42]. We decided against this design, however, in order to prevent users from thinking that the system was not working when receiving no response to their request.

2. Assembling research teams: My Colleagues also provides a simple mechanism to label and organize groups of colleagues. The primary use of these groups is to manage the flow of biographical documents among them. The rationale for this feature is that many collaborations in academia arise within the context of pursuing a particular funding opportunity. Since one key activity in preparing grant applications is collecting biographical information from each team member, it was logical to add functions to Digital|Vita to support this effort. Users can create any number of named groups drawing from their list of colleagues on record in the system. As in real life, individual colleagues can belong to more than one group. Groups can be annotated with relevant information, for instance with the identifier of the funding opportunity the group is working on.

3. Managing biographical document flow: Once a Digital|Vita user has created a named group, he or she can issue an electronic request to the group specifying the type of document requested (eg, NIH biosketch), the purpose for the request, and the date the information is needed by. Team members respond to requests through the system, which gives each person the opportunity to customize the requested document before it is sent. Digital|Vita issues automatic reminders to team members who have not responded by the due date. (Requesting documents in this manner is also possible between individuals.) The status of requests to and from other colleagues, as well as responses, is tracked in a Document Inbox. The Document Inbox allows users to send or request a document, as well as view and manage their recent document requests. Historical requests are accessible through a link to an archive. Before sending a document, users can preview it to ensure they are sending the correct document and that it contains the desired information. If new additions to the user's biographical information have been made, the document can be edited directly before sending. Users can also decline a document request. Requests are archived automatically after the due date of the document has passed or when the user has sent the requested document.

In summary, maintaining, formatting, and semiautomated updating of biographical information; searching for experts; and building and maintaining the social network and managing document flow are three sets of services designed to make the process of finding collaborators more efficient and effective and so facilitate the establishment of collaborations. We have focused on describing the Digital|Vita functionality as separate services in order to allow other researchers and developers to implement them selectively or all together in other systems.

Additional Information About Digital|Vita

The preceding section presents a relatively abbreviated description of the functionality of the Digital|Vita system. A video illustrating a prototype of the system and its use is available in the Multimedia Appendix. In addition, the final report (dated July 2007) about the Digital|Vita prototype project, which includes a comprehensive description of the problem space, research, and development methods and the Digital|Vita design and functionality, including the design rationale, is available online. At present, the Digital|Vita development team is writing detailed system specifications for the development of a production application.

Discussion

The problem of connecting scientists with each other is not new. However, doing so efficiently and effectively has taken on particular relevance and urgency in an age when much of science is migrating to a multidisciplinary, collaborative, and team-oriented model. At the same time, while electronic systems to help connect scientists have existed for some time, to this point they appear to have played only a minor role in helping scientists form collaborations.

Systematic approaches to designing systems to help researchers find collaborators are only in their infancy. We began this study with two basic research questions: (1) What requirements should systems for finding collaborators in biomedical science fulfill? and (2) Which information technology services can address these requirements? We believe that we have made an important contribution to the design of expertise locating systems with regard to both questions. The five main themes we have identified as requirements for such systems (compatibility,

communication, intermediation, information quality and access, and motivation) show that collaboration seeking is a complex activity that does not depend simply on the ability to retrieve factual information about potential collaborators. It is clear from our exploration of these themes that social connectedness, personal and professional compatibility, and power differentials influence the formation of collaborations. This means that systems that do not model and leverage the social context are at a clear disadvantage in satisfying the social requirements for establishing collaborations.

On the other hand, a rich informational representation of potential collaborators also appears to be important. Checking PubMed and Google for publications of a potential collaborator was only a starting point for many of our interviewees. Detailed investigation included other information resources, such as the NIH's CRISP, as well as patent and other databases. Because of the fragmentation of information about potential candidates, a thorough background search on potential collaborators is time and effort intensive. The cost of a search, therefore, appeared to be a barrier to finding the most appropriate and qualified collaborators. It was therefore logical for our design to focus on the most comprehensive and up-to-date, but customarily also least accessible, information profile available: the CV of the individual scientist.

Systems such as the Community of Science have long made biographical information a centerpiece of researcher profiles. Why do we think Digital|Vita may succeed where others have failed? Digital|Vita is centered on one component of a workflow that scientists almost universally perform on an ongoing basis—maintaining and updating the CV—and adds functions to support the establishment of collaborations. This design mirrors Payton's [37] approach to use trails through an information space to identify individuals with common interests. In both cases, information useful for expertise location is a by-product of activities that are already being performed. In addition, CV maintenance in Digital|Vita remains in its local context. Moreover, institutions typically have idiosyncratic formats for CVs and evaluations, and thus systems designed to manage biographical information must be able to format it according to local requirements. To our knowledge, while DigitalVita includes this function, none of the major commercial expertise locating systems, such as the CoS, Collexis, and Research Crossroads, provide this functionality, which is a major barrier to their adoption.

Managing biographical information within Digital|Vita not only requires no extra effort from a scientist compared to the traditional approach, it actually reduces effort because the raw biographical information is converted automatically to several frequently used standard formats. Making this workflow a central feature of Digital|Vita may prompt researchers to at least explore the collaboration-seeking functionality of the system.

However, the simple availability of features to search for collaborators does not mean that they will be used. Encouraging researchers to seek collaborators through Digital|Vita as opposed to traditional methods faces significant obstacles. For instance, established researchers often are so well-informed and well-connected that they, on average, will outperform any electronic system. We therefore anticipate that Digital|Vita may be primarily attractive to younger scientists (who may be using social networking tools in their life outside of work) and scientists who are new to the University of Pittsburgh or who are planning to collaborate with individuals in disciplines that they are not very familiar with. Digital|Vita also faces a complex challenge in keeping information about a researcher private while at the same time marketing that researcher to maximum effect. We believe that the granular control Digital|Vita provides in determining what information is public and what is not will help individuals adjust their public profile to their preferences. Other potential barriers to adoption include establishing an initial critical mass of profiles adequate for finding and choosing collaborators and integrating the systems and its capabilities with the regular work practice of the institution and individual researchers.

Future work on the Digital|Vita system will take two major directions. After development and implementation of the production system, we plan to design additional functions intended to improve the matching process among potential collaborators. Most likely, this research strand will focus on the development of algorithms to help pinpoint the most promising collaborators and bring new potential collaborative opportunities to a researcher's attention. A second direction for the Digital|Vita effort will be to identify other information technology services to help scientists find and access resources that are useful for their work. For instance, we are currently working on a directory of computational resources at the University of Pittsburgh to support scientific problem solving.

It is clear that electronic systems in support of research, and specifically those supporting the establishment of collaborations, will become increasingly important in the future. As more and more science goes "digital," both in its execution as well as in its documentation, systems such as Digital|Vita will become essential to the everyday life and activities of scientists.

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Conflicts of Interest

None declared.

Multimedia Appendix

Prototype of the Digital|Vita system (Video)

[Quicktime Movie file (MOV), 33.6 MB - jmir_v10i3e24_app1.mov]

References

1. Weaver AC, Morrison BB. Social Networking. Computer 2008;41(2):97-100. [doi: 10.1109/MC.2008.61]
2. Adams JD, Black GC, Clemmons R, Stephan PE. Patterns of research collaborations in U.S. universities, 1981-1999. National Bureau of Economic Research Productivity Program Meeting; December 6, 2002; Cambridge, MA .
3. Katz JS, Martin BR. What is research collaboration? Res Policy 1997 Mar;26(1):1-18. [doi: 10.1016/S0048-7333(96)00917-1]
4. Arzberger P, Finholt TA. Data and collaboratories in the biomedical community. Report No. CREW-02-01. Ann Arbor, MI: Collaboratory for Research on Electronic Work, School of Information, University of Michigan; 2002.
5. Braun T, Schubert A. A quantitative view on the coming of age of interdisciplinarity in the sciences 1980-1999. Scientometrics 2003 Sep;58(1):183-189. [doi: 10.1023/A:1025439910278]
6. Zerhouni E. Medicine. The NIH Roadmap. Science 2003 Oct 3;302(5642):63-72. [Medline: 14526066] [doi: 10.1126/science.1091867]
7. Zerhouni EA. US biomedical research: basic, translational, and clinical sciences. JAMA 2005 Sep 21;294(11):1352-1358. [Medline: 16174693] [doi: 10.1001/jama.294.11.1352]
8. Zerhouni EA. Clinical research at a crossroads: the NIH roadmap. J Investig Med 2006 May;54(4):171-173. [Medline: 17152855] [doi: 10.2310/6650.2006.X0016]
9. Cech TR, Rubin GM. Nurturing interdisciplinary research. Nat Struct Mol Biol 2004 Dec;11(12):1166-1169. [Medline: 15578058] [doi: 10.1038/nsmb1204-1166]
10. Kraut RE, Galegher J, Egido C. Relationships and tasks in scientific research collaboration. Hum-Comput Interact 1987-1988;3(1):31-58. [doi: 10.1207/s15327051hci0301_3]
11. Contractor NS, Zink D, Chan M. IKNOW: a tool to assist and study the creation, maintenance, and dissolution of knowledge networks. In: Ishida T, editor. Community Computing and Support Systems: Social Interaction in Networked Communities. New York: Springer; 1998:201-217.
12. Contractor NS, Monge PR. Managing knowledge networks. Manage Commun Q 2002 Nov 1;16(2):249-258. [doi: 10.1177/089331802237238]
13. McDonald DW, Ackerman MS. Expertise recommender: a flexible recommendation system and architecture. In: Proceedings of the 2000 ACM Conference on Computer Supported Cooperative Work (CSCW '00). New York: ACM; 2000:231-240. [doi: 10.1145/358916.358994]
14. Erickson T, Kellogg WA. Knowledge communities: online environments for supporting knowledge management and its social context. In: Ackerman MS, Pipek V, Wulf V, editors. Sharing Expertise: Beyond Knowledge Management. Cambridge, MA: MIT Press; 2003:299-325.
15. de Vries S, Kommers P. Online knowledge communities: future trends and research issues. Int J Web Based Commun 2004;1(1):115-123. [doi: 10.1504/IJWBC.2004.004804]
16. Johnson CM. A survey of current research on online communities of practice. Internet Higher Educ 2001;4(1):45-60. [doi: 10.1016/S1096-7516(01)00047-1]
17. Millen DR, Fontaine MA, Muller MJ. Understanding the benefit and costs of communities of practice. Commun ACM 2002 Apr;45(4):69-73. [doi: 10.1145/505248.505276]
18. Ackerman MS, Palen L. The Zephyr Help Instance: promoting ongoing activity in a CSCW system. In: Tauber MJ, editor. Proceedings of the SIGCHI Conference on Human Factors in Computing Systems: Common Ground (CHI '96). New York: ACM; 1996:268-275. [doi: 10.1145/238386.238528]
19. Jacovi M, Soroka V, Ur S. Why do we ReachOut?: functions of a semi-persistent peer support tool. In: Proceedings of the 2003 International ACM SIGGROUP Conference on Supporting Group Work (GROUP '03). New York: ACM; 2003:161-169. [doi: 10.1145/958160.958186]
20. Mattox D, Maybury MT, Morey D. Enterprise expert and knowledge discovery. In: Bullinger H, Ziegler J, editors. Proceedings of the HCI International '99 (the 8th International Conference on Human-Computer Interaction) on Human-Computer Interaction: Communication, Cooperation, and Application Design. Volume 2. Mahwah, NJ: Lawrence Erlbaum; 1999:303-307.

21.   Friedman PW, Winnick BL, Friedman CP, Mickelson PC. Development of a MeSH-based index of faculty research interests. Proc AMIA Symp 2000:265-269 [FREE Full text] [Medline: 11079886]

22.   Streeter LA, Lochbaum KE. Who knows: a system based on automatic representation of semantic structure. In: RIAO 88 Program: Conference with Presentation of Prototypes and Operational Demonstrations, User-Oriented Content-Based Text and Image Handling. Paris, France: CID; 1988:380-388.

23.   Mockus A, Herbsleb JD. Expertise browser: a quantitative approach to identifying expertise. In: Proceedings of the 24th International Conference on Software Engineering (ICSE '02). New York: ACM; 2002:503-512. [doi: 10.1145/581339.581401]

24.   Flynn DA. Seeking peer assistance: use of e-mail to consult weak and latent ties. Libr Inform Sci Res 2005;27(1):73-96. [doi: 10.1016/j.lisr.2004.09.005]

25.   Lampe C, Ellison N, Steinfield C. A face(book) in the crowd: social searching vs. social browsing. In: Proceedings of the 2006 20th Anniversary Conference on Computer Supported Cooperative Work (CSCW '06). New York: ACM Press; 2006:167-170. [doi: 10.1145/1180875.1180901]

26.   Ehrlich K. Locating expertise: design issues for an expertise locator system. In: Ackerman MS, Pipek V, Wulf V, editors. Sharing Expertise: Beyond Knowledge Management. Cambridge, MA: MIT Press; 2003:137-158.

27.   ; Community of Science: resources for research, worldwide. Who we are. Community of Science. 2008. URL: http://www.cos.com/about/ [WebCite Cache ID 5Vnr0FEwN]

28.   Baum A, Calesnick LE, Davis GE, Gatchel RJ. Individual differences in coping with crowding: stimulus screening and social overload. J Pers Soc Psychol 1982 Oct;43(4):821-830. [doi: 10.1037/0022-3514.43.4.821]

29.   McDonald DW. Evaluating expertise recommendations. In: Ellis C, Zigurs I, editors. Proceedings of the 2001 International ACM SIGGROUP Conference on Supporting Group Work (GROUP '01). New York: ACM; 2001:214-223. [doi: 10.1145/500286.500319]

30.   Beyer H, Holtzblatt K. Contextual design. Interactions 1999;6(1):32-42. [doi: 10.1145/291224.291229]

31.   Beyer H, Holtzblatt K. Contextual Design: Defining Customer-Centered Systems. San Francisco, CA: Morgan Kaufmann; 1998.

32.   Glaser BG. Basics of Grounded Theory Analysis: Emergence vs. Forcing. Mill Valley, CA: Sociology Press; 1992.

33.   Mattessich PW, Monsey BR. Collaboration: What Makes It Work. A Review of Research Literature on Factors Influencing Successful Collaboration. St. Paul, MN: Amherst H. Wilder Foundation; 1992.

34.   Fiore AT, Donath JS. Online personals: an overview. In: CHI '04 Extended Abstracts on Human Factors in Computing Systems. New York: ACM; 2004:1395-1398. [doi: 10.1145/985921.986073]

35.   Merkle ER, Richardson RA. Digital dating and virtual relating: conceptualizing computer mediated romantic relationships. Fam Relat 2000 Apr 9;49(2):187-192. [doi: 10.1111/j.1741-3729.2000.00187.x]

36.   Lutters WG, Ackerman MS, Boster J, McDonald DW. Mapping knowledge networks in organizations: creating a knowledge mapping instrument. In: Chung HM, editor. Proceedings of the Sixth Americas Conference on Information Systems (AMCIS '00) [CD-ROM]. Atlanta, GA: AIS Press; 2000:2014-2018.

37.   Payton DW. Discovering collaborators by analyzing trails through an information space. In: Jensen D, Goldberg H, editors. Proceedings of the AAAI Fall Symposium on Artificial Intelligence and Link Analysis. Menlo Park, CA: AAAI Press; 1998:84-87.

38.   Grudin J. Why CSCW applications fail: problems in the design and evaluation of organization of organizational interfaces. In: Proceedings of the 1988 ACM Conference on Computer-Supported Cooperative Work (CSCW '88). New York: ACM; 1988:85-93. [doi: 10.1145/62266.62273]

39.   Yang SJH, Chen IYL. A social network-based system for supporting interactive collaboration in knowledge sharing over peer-to-peer network. Int J Hum-Comput St 2008 Jan;66(1):36-50. [doi: 10.1016/j.ijhcs.2007.08.005]

40.   McDonald DW. Recommending collaboration with social networks: a comparative evaluation. In: Proceedings of the SIGCHI Conference on Human Factors in computing Systems (CHI '03). New York: ACM; 2003:593-600. [doi: 10.1145/642611.642714]

41.   Terveen L, McDonald DW. Social matching: a framework and research agenda. ACM Trans Comput-Hum Interact 2005;12(3):404-434. [doi: 10.1145/1096737.1096740]

42.   Aoki PM, Woodruff A. Making space for stories: ambiguity in the design of personal communication systems. In: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '05). New York: ACM; 2008:181-190. [doi: 10.1145/1054972.1054998]

Abbreviations

CI: contextual inquiry
CRISP: Computer Retrieval of Information on Scientific Projects
CV: curriculum vitae
NIH: National Institutes of Health

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