Empathic Communities: *Reaching Out Across the Web*

Jenny Preece

As a child, I was told that "a trouble shared is a trouble halved." People need to discuss their problems, particularly medical problems. But in this fast-moving, modern society, it can be difficult to find listeners who understand the problem. Howard Rheingold [17] has shown the power of online communities in his thoughtful portrayal of the WELL[1]. Now, with tens of

thousands of online communities, new support groups emerge daily. These communities encourage learning through shared experiences. They enable participants to offer and receive emotional support in a climate of trust, equality, and empathy.

The days are gone when doctors had time to call at patients' homes to talk. A recent article in the *Guardian,* a British daily newspaper, reports that "research has shown patients enjoy on average 16 seconds to explain their view of their medical problem to doctors" [24]. Some doctors also think that patients do not need to know details about their condition. Furthermore, patients often fear offending their doctor by seeking a second opinion.

An increasing number of people are looking to the World Wide Web to help solve their medical problems. A *New York Times* journalist [25] reports how Mallory Marshall and her husband searched the Web to learn about prostate cancer. "We became very well informed," Marshall said. "With the information I dug up, we went all over the place to interview different doctors and compared different therapies ranging from radiation, diet, surgery and 'seed' implants."

Time constraints can make it difficult for people to attend local support groups, so many people are turning to the Web to meet others. Instead of meeting 5 or maybe 10 other patients with the same problem, it is possible to reach hundreds and to find people of the same age and gender. Distance and time are no longer serious barriers to communication. Comparing stories about diagnoses and treatments makes patients better informed, so that they can refine their questions for those precious moments with their doctor.

Talking with other patients is a way of finding out what to expect next during illness. Physicians know the facts, but patients who share the same experience can empathize with others' conditions and feelings. The term "empathy" has at least three different meanings. It can mean knowing what another person is feeling, feeling what another person is feeling, or responding compassionately to another person's distress [12, p. 234].

In a review of more than 100 online communities, we found that empathy is a key ingredient in many support groups covering a wide range of topics [15]. I therefore refer to groups, in which communication between members is strongly empathic, as empathic communities to distinguish them from groups that are primarily concerned with factual information exchange. Empathic communities generally have a strong focus on medical or personal problems, and their members want empathy and emotional support. In one online medical support group this strong sense of empathy was summed up in comments from three participants:

"We're all in this together, which helps!"

"Thanks for this list – it is nice to know you're not alone".

"Dr. S and Dr. B said they were amazed at how well I was recovering and give credit to 'my good attitude and emotional preparation for surgery' I thank you all for much of that, thank you for your positive support."

Characteristics of these groups vary; some of the most strongly empathic groups are closed or have mechanisms that discourage aggressive or superfluous posting. For example, they may have joining rules and by-laws on the form and content of messages. Some have moderators who check all messages before posting them to the community. Others have mediators who are notified by members when they observe unreasonable behavior. The mediator then investigates the problem. The amount and type of activity and the demography of a community's population define its character too.

Design of the supporting software influences community behavior. Most bulletin boards have threading, by which replies to topics are listed below the original message. Some indent messages to distinguish replies

[1] The WELL was one of the first online communities. It was started by a group in the San Francisco Bay area.

and replies to replies. Some support the use of emoticons and small icons to signal content type. Searching by date, name, or topic is becoming increasingly common. Web resources such as frequently asked questions (FAQs), descriptions of medical conditions and treatments, and lists of resources influence online behavior. Relationships with physical communities, such as the Blacksburg Electronic Village [5, 6], and organizations such as The National Cancer Institute influence electronic communities. These attributes apply to the case story discussed later and combinations of some of them feature in most communities [23].

Last year I became intensely interested in one particular discussion group, which, as I discovered, is a strong empathic community. I needed to find out more about a skiing injury, in which I tore the anterior cruciate ligament—or ACL as it is generally known—in my right knee, an injury suffered by more than 20,000 skiers in the United States each year, as well as by numerous basketball, football, and tennis players. The associated Web pages provided basic information, but reading the messages quickly turned me into a knowledgeable patient. However, what impressed me most were the support and empathy among the members of this community.

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Medical Background of the Community

The ACL is one of four major ligaments that supports each knee. Without it, a knee tends to slip sideways and may give way. Getting this injury is bad news because patients have to give up sports for several months. Even though the injury is common and not life-threatening, the changes in life circumstances that it brings for people passionately involved in sports can be frustrating and depressing.

There are two main ways of treating a broken ACL. The ligament can be reconstructed by surgery, or surgery can be avoided and instead, the patient can follow an intensive program of physical therapy to strengthen surrounding muscles to compensate for the missing ligament. Surgery tends to be the favored option by athletic people because for most people it brings nearly full recovery and a return to sporting activities. However, recovery may take a year and be painful.

The choice of treatment is, however, not as straightforward as it might seem. If surgery is chosen, patients must choose among different versions of the reconstruction. Furthermore, patients need to remember that people respond differently to treatments, have different tolerances to pain, and experience varying recovery times, so what works for one person may not work for another. Age, gender, body weight, life circumstances, and attitude also vary from person to person and influence the success of the surgery. Of course, the skill of the physician is also an important variable. Having made a choice, the patient then has to work through the recovery phases, which may be tedious and painful. In addition, there may be stresses associated with changes of life circumstances after surgery and the uncertainty of whether full recovery will be achieved.

Orthopedic surgeons can answer medical questions and may be able to draw on the observations of hundreds of patients, but most patients want to know what it was really like for other patients. They want to hear first-hand accounts of their experiences. How

much did it hurt? How does what I am experiencing compare with what you experienced? If I do this, what should I expect? One way of getting answers to such questions is to seek other patients on Web bulletin boards, of which there are now several thousand. Some are produced as suites of boards by the same originators, and some, like Bob's bulletin board, are the work of caring individuals who want to share their experience and help others.

Bob's ACL Bulletin Board

The ACL bulletin board, known eponymously as Bob's bulletin board, forms part of an ACL Web site. The bulletin board (URL: http://www.cnct.com/~bwillmot/knees/wwwboard/) started in April 1996. The number of postings per day increased from about 24 in May 1996 to more than 100 in April 1997. By October 1997 there was an archive of about 9,000 messages. Messages are threaded so that the headers of responses are indented and positioned below the header of the message to which the reply applies. The bulletin board is rudimentary. Messages cannot be ordered and searched by date, topic, or sender's name. Some people use log-in names, some use first names, some full names, some just give initials, and some give a description. There are no guidelines on how to specify topic lines, so styles vary and some are more helpful than others. Examples of typical topic lines are:

Help … Tomorrow is D-Day! (reference to surgery)

I don't know what to do!!! (reference to just discovering the extent of his injury)

Man, I AM NERVOUS! (concern not only about having surgery the next day, but also about whether he will be able to play football again)

Although guesses can be made about what follows, the topics being discussed are not obvious.

The gender ratio is close to two males to one female and is similar to that reported by Pitkow and Kehoe[13] for the general population of Internet users. In 1996, when the board started, there was a higher proportion of men. In a pilot study in March 1997 the gender ratio was 4 males to 1 female. Most posters are between 20 and 40 years old and share a strong love of sports. This provides a clear focus for the group and common understanding between them, which undoubtedly contributes to the success of the community [23]. The scope of most discussions tends to be narrow and clearly focused. The bulletin board is open to anyone, so the occurrence of acrimonious posts (flaming) and spamming would not be surprising but such behavior is unusual. Bob lightly reviews messages, but he rarely intervenes.

Part of the membership of the ACL community appears fairly transient. Most of the new people on the board have recently sustained the injury, but there are a few old-timers who keep coming back. There have been a few postings from people professionally involved in orthopedic treatment, such as a nurse and a specialist in knee braces, but there is no sign of physicians. The tone of the messages suggests a sense of equality and trust within the group. Communication between members is helpful, empathic, often altruistic, and sometimes cathartic. People want to share their experiences, learn from others, and support each other.

What Do People Talk About?

A content analysis of 500 archived messages, from the ACL bulletin board, sampled in batches of 100 at approximately two-monthly intervals, was analyzed [14]. Some 312 messages were posted by men, 156 by women, and 32 could not be classified by gender. Two hundred fifty-one different people posted these messages. The largest number posted by one person (Bob) was 24. Most of his posts were to draw attention to previous posts on a topic of interest. For example, common topics that newcomers ask about include Is surgery necessary? What is the difference between different surgical procedures? How long is recovery? and so on. At the time of this study additional useful information, including a video of arthroscopic surgery, was available on the Web site, but FAQs were not included. One hundred fifty messages were single posts by one person. Figure 1 summarizes these findings. A detailed discussion of the analysis and the methodology used in this study is contained in Preece [14].

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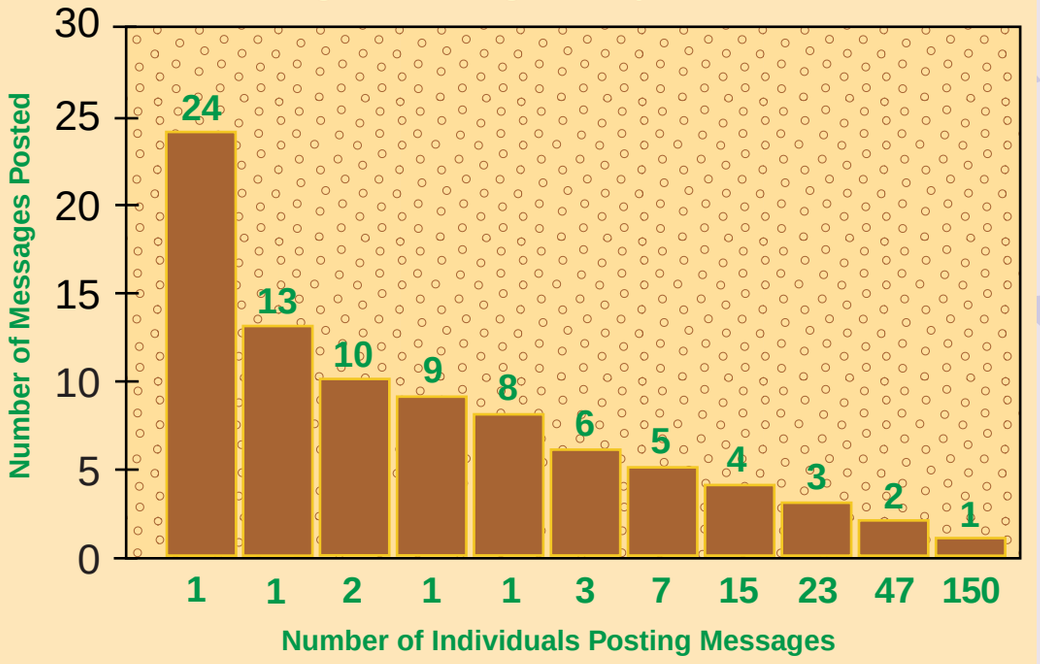
Figure 1 Messages sent per individual



The analysis showed that 76.8 percent of the posts were empathic to some extent. Some directly asked for or offered support, some simply told their story, many asked or answered questions by drawing on their own personal context. The side-bar titled "Examples of Communicating Empathy" (pp. 40-41) gives examples of some of the different ways of communicating empathy.

Only 17.4 percent of the postings were purely factual questions or answers and showed no empathy or reference to personal experience, as illustrated by the examples in the sidebar titled "Examples of Communication without Empathy." (p. 39) Some 5.8 percent fell into the category of "other," and most of these were jokes. Occasionally there are signs of frustration, when newcomers, anxious to find out more about their recently suffered injury, ask basic questions that have been discussed many times before. Usually someone politely refers the inquirer to an earlier discussion. The community is surprisingly tolerant and annoyance is rarely shown.

Different Needs at Different Times

Not surprisingly, patients' needs change between the time of their injury and their recovery. The kinds of questions asked changes and so does their need for empathy. Furthermore, the balance between needing information and needing empathy varies too. The patients' messages suggest that three main stages can be identified along the path from injury to recovery: from injury to diagnosis, from diagnosis to treatment, and from treatment to recovery, as shown in figure 2.

Some people get their injury diagnosed very quickly, others need to visit two or more doctors and may seek the confirmation of a magnetic resonance imaging test (commonly called an MRI). At this first stage, the factual content of messages is about details of diagnosis and the kinds of treatments that are available. The empathic comments generally consist of people telling their stories, including frustrations about not being able to play sports and concerns about how long it will be before they can play again.

The time between diagnosis and deciding on treatment is when the most detailed factual questions are asked. Patients want to find out about different treatments, check their understanding of the procedures involved, get estimates of the likely amount of pain and discomfort, and check the prognoses for recovery. They also want to hear from others who are further along the path to recovery. Patients also get frustrated and scared and seek the support of others, but the need for factual information seems to dominate at this stage.

After treatment, which for an ACL injury generally means some form of surgery, patients are eager to hear how their experiences compare with those of others. This is the time when empathy is strongest, especially for patients who experience pain, who are not sleeping well, and who wonder how long they

will feel like this. The lucky ones want to check their progress with others who have gone before them. Some people count the days until they can resume their favorite sports— biking, football, skiing, and so on—and want information about the best physical therapy workouts to get them back playing again.

People vary enormously, but in general the time before treatment is when most fact finding occurs, with the time just after diagnosis being the most intense of all. The same questions frequently get asked again and again. Empathic messages are sent at all stages, but the need for empathy is often strongest just after surgery.

The messages sent to Bob's bulletin board illustrate the important role of empathy in this community. People want to make contact with others, tell their stories and be heard, offer and receive support, as well as get factual information about their problem. Learning the medical facts is only part of the communication on this board. Even those who ask or offer factual content usually do so in the context of their own injury, recovery, and broader life circumstances. These messages are from patients concerned about their condition and it is common for them to talk about their own experience. Messages from other patient support groups also show a high level of empathy [15]. Women's health groups are often the most strongly empathic, particularly those that have joining requirements and rules and are moderated.

Research in psychotherapy [7, 9] informs us that empathy is present in most communication, but in many work situations it may be subtle. Much of the research in computer-supported co-operative work (CSCW) and computer-mediated communication (CMC) focuses on performance in formal tasks, where empathy is usually not obvious. The dramatic increase in empathic communities provides exciting opportunities for researchers to take a new perspective that acknowledges the role of empathy in informal online communication.

Design Implications

The ACL bulletin board, like many bulletin boards, has little structure and is an example

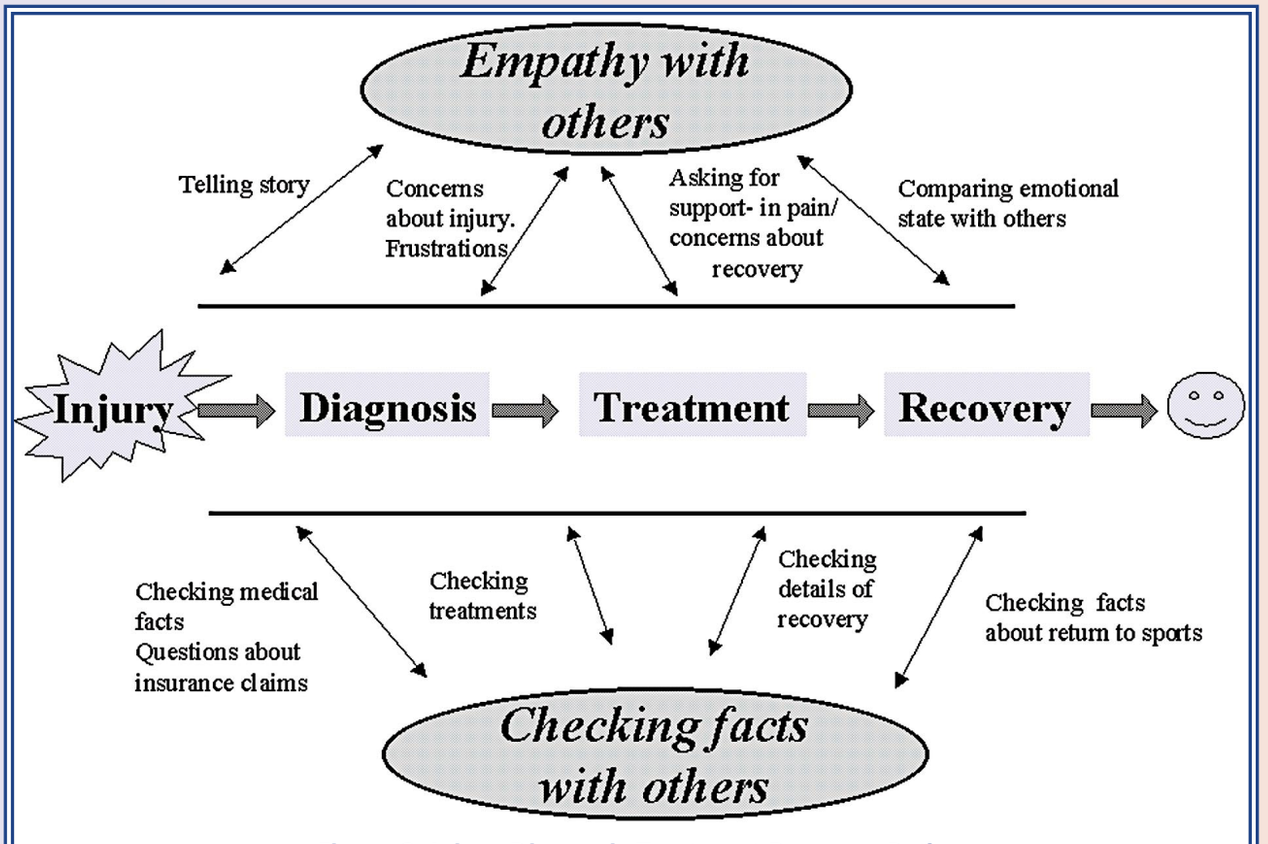


Figure 2. Injury-Diagnosis-Treatment-Recovery Path

of the ad hoc evolution of bulletin board design [8], which is just beginning to change as designers become more conscious of communities' needs. Basic tailoring facilities and emoticons are examples of change. As the number of people online increases, users will request better usability. For example, they will question why they cannot do seemingly straightforward things, like easily search previous messages and archives. Some ACL patients wanted to contact others similar to themselves. Another issue discussed was the frustration experienced when newcomers ask questions that have already been discussed at length. In addition, ways of dealing with well-known problems, like flaming, continue to be important for all communities.

Figure 3 shows some key design requirements for empathic bulletin board communities. At first glance these issues appear like those needed by any online community. Empathic communities are at the extreme end of the empathic–non-empathic spectrum of communities. The difference lies in the degree to which supporting empathy is emphasized. In order to support the high level of empathy that makes empathic communities function, their requirements need to be met in ways that do not threaten empathic communication. There may, therefore, be times when efficiency has to be balanced against supporting empathy and trade-offs made. For example, FAQs are efficient but may affect empathy among patients, as discussed later. Similarly, a balanced approach is needed to developing techniques for information searching and other key user activities (see Figure 3, center of diagram). Ways of dealing with concerns such as privacy (left of diagram) may require more human involvement than in other communities. People in distress also tend to be vulnerable, so guarding against misleading information (particularly medical information), impostors, and

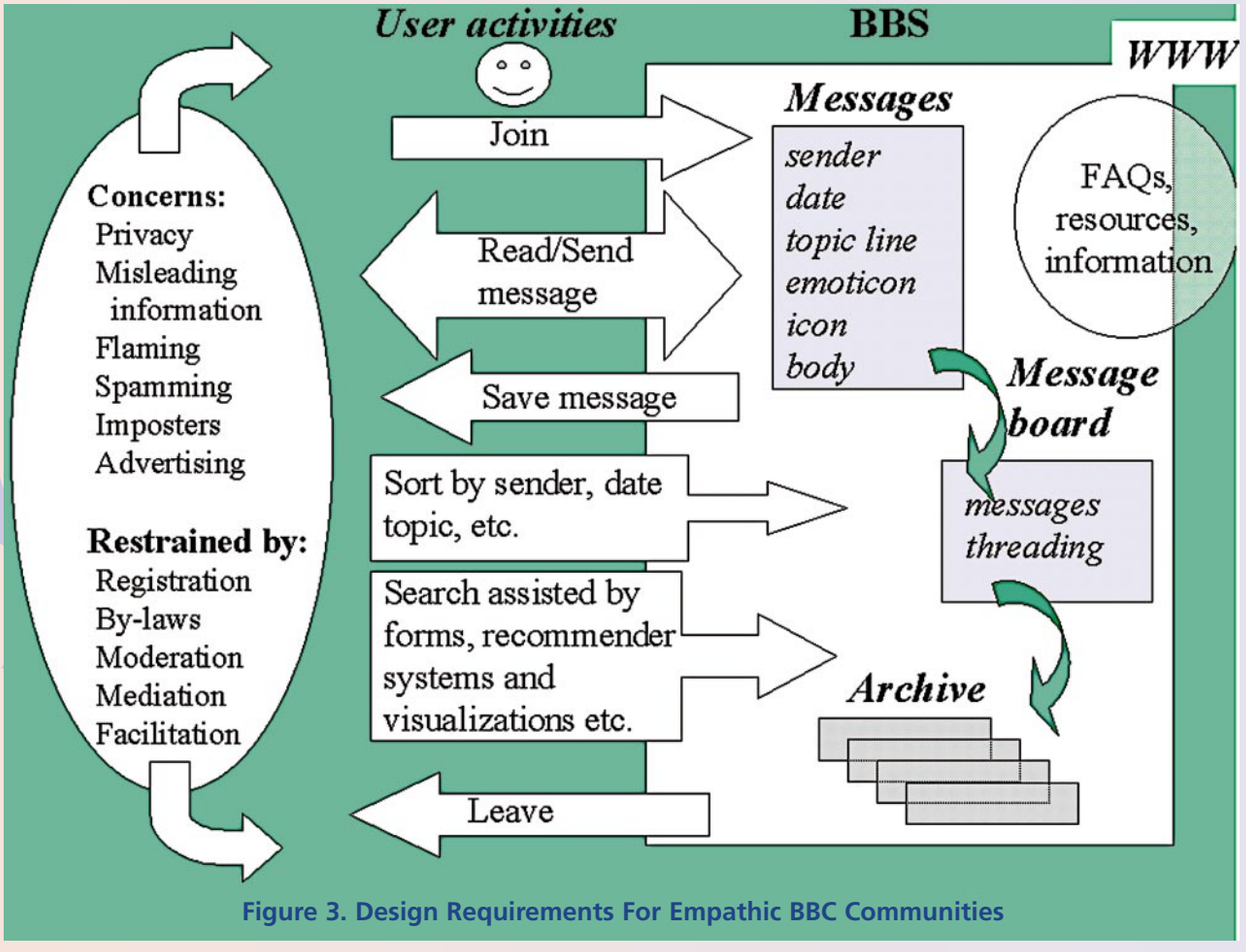


Figure 3. Design Requirements For Empathic BBC Communities

scams is a serious issue. Good resources on the Web (top right of diagram) are also needed, with ways of accessing them within a bulletin board (right of diagram). For example, it would be helpful to click on a term in a message and call up a Web browser. Tailoring the bulletin board display and keeping personal files is useful too.

Finding Facts and Others Like Yourself ...

Most people join Bob's bulletin board soon after their ACL injury. They want to find out as much as possible about the various treatment options available. Sometimes, people also want to find others with whom they can closely identify in terms of gender, age, life circumstances, sports preferences, level of sports activity, and body mass to see what choices they made and how successful they were. For example, a patient might want to find women over 40 years of age weighing around 120 pounds who are moderately active. The patient might want to gauge where the women are in the recovery process, to review their messages and others in the same thread or on related topics. Now the only way to do this is to scan the list of names for those that look female or post asking people who fit the description to identify themselves. Having found potential candidates, the next stage might be to contact them directly.

Providing this functionality raises privacy as well as technical issues. People may not want to receive e-mail from strangers, so making this easy would not be desirable. Other solutions need to be found. For example, people could be invited to complete a simple online form that would be active for a limited period of time and then be either renewed or discarded. There could be a facilitator who ensures that requests for contacts are honorable and agreeable to the person being asked. The facilitator would then initiate an introduction.

Information visualization techniques, like those used in the FilmFinder [2], could enable participants to visualize data from community members collected via forms. It would be possible to use such techniques to visualize the relationships between combinations of variables such as age, gender, time since the accident, time since surgery, and so on. Searching strategies can be adapted on the basis of visual feedback to enable users to target specific individuals.

Research on recommender systems may also be useful in this context. Recommender systems are like collaborative filtering, but the term is broader and includes systems that may not explicitly collaborate with recipients [16]. Some of these systems enable users to enter their preferences directly, in addition to the system tracking choices from past user behavior. Using such systems, it might be possible to alert members of communities to posts that might be of interest to them. Users could then decide whether they want to follow up on the recommendations. GroupLens [11], for example, performs a similar service for Usenet readers. Studies of GroupLens indicate that that the service is useful. However, it was difficult to get adequate ratings upon which to base future searches because of the small number of articles read by each Usenet user. The narrow focus of many empathic bulletin board communities may be a successful avenue for exploring such systems.

One problem with these suggestions is that they have implications for individuals' privacy, which must be protected. A second is that they involve substantial software development. In the short term improved ways of tailoring bulletin board displays and bookmarking would improve usability. Some

Examples of Communication without Empathy

Fewer people asked straight factual questions or gave answers in which there was little or no reference to their own personal situation, such as the comments from Gerry and Rob.

Hard to say if she has a problem or not. Just make sure that when she's not rehabing it all her spare time is spent trying to straighten the leg.

Gerry

Well isometrics are a good way to exercise the legs without putting undue stress on the compromised ACL. . . . Straight leg lifts — lay on your back and while keeping your knee straight lift your leg 10 to 30 degrees, Hold. Repeat. Once again the amount of time you hold the leg will determine the amount of work the quad will do.

Rob

agreed formats for message headers (e.g., topic lines and user names) would also help.

Same Questions Again and Again

When I joined the ACL community I wondered why there were no FAQs on the associated Web pages. Later, as I used the board more, I realized that, as with many obvious solutions, there could be a serious problem with this one. Providing concisely written answers in FAQs may inhibit people from asking questions in case they are thought unnecessary and a nuisance by others. FAQs might encourage intolerance and abruptness. Comments like: "you should check the FAQs first before posting" or "don't waste people's time by asking questions that are already answered in the FAQs" could reduce or even eliminate empathy and change the nature of the community. Since I conducted the study, FAQs have been added to the Web site. So far, my concerns about destroying empathic communication have not been borne out and I hope they will not.

A balanced approach to supporting efficient information exchange and empathy is needed, and the solutions may vary from one community to another depending on the nature of the community, the topics of discussion, and the structure and usability of the supporting software. For example, Ackerman and Palen [1] observed a different solution in their study of the Zephyr system, which is a conferencing system used by students at the Massachusetts Institute of Technology to discuss programming problems. They concluded that there was no need for a system memory because the users did not mind answering the same questions again and again. Of course, discussions of technical issues are likely to be less empathic than personal health. In a study of the general use of e-mail in a professional setting, Whittaker and Sidner [22]point out that many e-mail conversations are multi-

Examples of Communicating Empathy

In the sequence of postings that follow, Debbie directly asked for support and Ken, Kath, and Mike responded by empathizing with her situation and suggesting ways to cope. Notice also the expression of warmth and encouragement to "hang in there," an invitation to come back and tell how she is progressing, a note that she is welcome to contact the other "veggies" at any time, and wishes of good luck. Considering these people only know each other through this bulletin board, the warmth, caring and empathy conveyed in their postings is remarkably strong.

It's been two weeks and five days now. I read other postings where others pained over feeling alone. Well, I'm having my bout with the depression. It's a battle to entertain my mind, reading, computer, talk, radio and rarely TV. . . . I suppose not sleeping very well is wearing on me as well as some of you. Not happy with my flexion yet, can't seem to get that last 1/8th inch. Thanks for listening. :)

Debbie

My feeling is that nobody knows what we are going through. A lot of my friends have had this, and though they know it is a terrible time, they can look back on it—we will be able to do this too, one day but for now . . . I kind of feel alone. For me, I just want to sleep 3 hours straight, just once. I guess what I am saying is that I know what you are saying. We just have to hang in there. Good luck.

Ken

Debbie, . . . I haven't been sleeping very well either. Just hang in there you are not alone. Keep me updated on how you are doing.

Kath

While you're a few days further in than me I feel I have too much of a job to do to feel alone (getting better that is) . . . I HAVE watched over a dozen movies . . . mostly of the intelligent variety, . . .You might want to try this. I made a list of 12 movies I've been wanting to see (Room with a view, Forrest Gump . . .) Anyway if that doesn't help, you can always communicate with us other "veggies" any time.

Warm regards,

Mike

The next three comments show empathy about life circumstances. Dave is frustrated that he can't ride his bike in the beautiful weather. Brad and Bill

threaded; that is, several conversations are going on at the same time, so information gets lost and the same questions are asked again and again. The authors do not mention whether this is a problem.

Sensitive Moderating, Joining Requirements, and By-Laws

Many concerns for empathic communities can be restrained by unobtrusive moderation of some form, rules, and by-laws. Several roles have been identified for moderators of online communities [e.g., 4] in addition to stopping flaming and other antisocial behavior. Some moderators lead discussions and keep them on track, but this is less important for empathic communities than for many other groups. Moderators may also act as experts, answering questions or directing people to previous messages or resources, as Bob does for the ACL group. Moderators of empathic communities may need to take more diverse roles, channeling discussion of different topics, maybe encouraging people to seek expert advice, keeping watch for scams, and so on. In particular, as groups get very large, moderators will need to create meaningful subgroups for discussion of specific topics. Deciding when to do this could be a sensitive issue for empathic communication. It is well known that moderators change the nature of online communication [11, 21, 22], and supporting empathy requires skill. Mediators are becoming more widespread. Unlike moderators, mediators only take action when called to do so by the community.

As well as ensuring that an empathic climate prevails, moderators need to look out for people posing as medical experts or counselors. It is easy to imagine instances of people posing as professional medics in order to give, or worse, sell advice. There has been no evidence of this behavior on Bob's bulletin board, but it could be a concern. Incidents of

respond with comments about their own situations, which they point out are worse but in a friendly, joking manner which is supportive.

AAAAAAAAAAAACCCCCCCCCCCCCCK-KKKKKKKKKKKKK!!!!!!!!!!!! There, I just had to get that off my chest. It's 50 degrees today for the first time since Nov. and the sun shining. I have a beautiful bicycle waiting to be rode and the road is calling. BUT doc says no. Oh well I knew you would understand fellow bad knees. Thanks for listening to my whining. Now I feel better!

Dave

Before you know it, it will [be] 70-80 degrees out and you will be out pedaling your ass all over town! I was to have my recon on 3/3, now I have to wait until 4/4, just think how warm it will be before I get out.

Brad

Morning Dave, You make me laugh. . . . Don't you like hour after hour on your trainer . . . be glad you don't live in Central California where it's now 70+ degrees, flowers blooming and you can't hit the road.

Bill

Some people use the board to tell their story and as a way of inviting others to contact them. The story below from Jimmy is an example of this. He is not asking questions; he tells his story and presumes that when he comes back with more details about his physical therapy, people on the board will be interested in listening. He also wants to encourage and support others.

Well, here is my story. It all started on 1-11-97, I am 26 and I have been skiing for 11 years with no injuries until now! It all started with the "famous" one last run. . . . I was so glad to find out that the pain could be controlled, just take the meds as prescribed, don't try to be a hero, it WILL hurt. . . . I have been reading all these stories for the last couple of months and they have been a tremendous help, so please feel free to ask any question, seeing I should have some free time on my hands for the next couple of weeks!! I will be writing back with some PT details as they become available.

Jimmy

Jimmy's story is typical of an indirect request for empathy. He does not ask for support or help directly but instead tells his story, which often has the effect of eliciting empathic responses. In our study we observed that men adopted this approach more frequently than women, who made more explicit requests for empathy. The men in this study also asked more factual questions than women [14].

people posing as someone else [17] and gender swapping have been well documented [18, 20]. Impostors selling expensive homeopathic medicine, promising miracle cures, were observed in several empathic groups. Warnings spread through the groups very quickly but some people made purchases before the scam was exposed. Awareness that people are watching for scams may deter them, but the problem is likely to increase as more people come online.

Joining requirements may also become more widespread to discourage those without bona fide interest. More public explanations of moderators' roles and clear descriptions of community rules might help discourage unacceptable behavior and support empathy. Further research is needed into the details of these issues in relation to empathic communication.

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Private Communication

Private communication channels are useful for contentious one-to-one debate, for discussing topics of narrow interest or a personal nature [1]. Furthermore, there are limits to the amount and kind of information that a person will make available to the public at large, so private forums for communication are needed [10]. One-to-one communication is also known to be liked by women and girls [19]. Facilitating private communication is likely to encourage empathy, particularly when the topics of discussion are personal.

Balancing Empathy and Factual Information Exchange

The social ecology of human groups is delicate. Just as in ecosystems of animals and plants, the nature of the dynamics of human social ecology is that many variables are interrelated. Change one and there can be a ripple of change through the whole system in unexpected ways. The dynamics of online communities that have only text as a medium for expression may be even more sensitive because they lack so many of the feedback cues that we are used to in face-to-face communication. Even quite small changes to the physical (i.e., software) and social structures of the community can have a big impact on the way it functions.

Communities are forming on the Web at a phenomenal rate for all kinds of purposes [3, 13]. By better understanding the role of empathy in a cross-section of these communities, we can investigate and design tools to support empathic communication as well as factual information exchange. Well-designed empathic communities will improve the quality of life for thousands of people.

Acknowledgments

I wish to thank Bob Wilmot for answering my questions and for developing Bob's bulletin board, which is a source of information and comfort to thousands of knee sufferers. Kambiz Ghozati did most of the data analysis for this study and provided many useful insights. I also thank the reviewers and editorial staff of *interactions* and Ben Shneiderman for their comments.

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