

## Empathic communities: balancing emotional and factual communication

Jenny Preece\*

*Information Systems Department, University of Maryland, Baltimore County, Baltimore, MD 21250, USA*

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### Abstract

The Web empowers a diverse population of users and this is reflected in both the demography and interests of today's on-line communities. Many of these communities provide an essential social function by enabling people with medical or personal problems to discuss their concerns with others. Physicians can provide the facts, but other patients can tell you what it really feels like and what to expect next, in a way that only someone with personal experience can. A study of the messages from an on-line medical support group shows that empathy is an essential ingredient in participants' discussions. Better tools are needed to empower patients to help themselves by finding information and contacting other patients in bulletin board communities. Suggestions about the nature of these tools are discussed. In particular, supporting a balance between empathic and factual communication is stressed. © 1999 Elsevier Science B.V. All rights reserved.

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### 1. Introduction

In the early days of on-line communities most discussion groups were developed for and used by technical people. This has changed. Today many more people have access to computers and on-line discussion groups through the World Wide Web (WWW) and other Internet services. The user population is becoming increasingly diverse in terms of gender, age, occupation, culture and computer expertise [1]. The number of people using computers in all age groups and for both genders continues to increase; in particular more women are finding their way onto the Internet than ever before [2]. Thousands of

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\* *E-mail address:* preece@umbc.edu (Jenny Preece)

communities are developing, supported by listservs, bulletin boards, UseNet groups, chatrooms, multi-user domains (MUDs/MOOs), and specially designed, complex, fantasy environments.

Many on-line groups provide much more than a forum for exchange of factual information, they also have a strong social support function. For example, a support group for people with back pain has far different needs than a group discussing the intricacies of Java programming. People in medical support groups want information about their condition, but many also want empathy from fellow sufferers. With so many different communities forming, it is timely to ask questions about why these communities develop; how they change over time; how they differ from each other in terms of demography, focus or purpose; and the behaviour of their members. How can we characterize them so that we can design software, which supports these different needs well? Further, as more people come on-line, the size of individual groups will increase too. Scalability will become an important design issue.

Ultimately, as designers, our goal is to understand how the answers to such questions imply the design of better tools and on-line community spaces. Effective design of on-line communities may become as important as effective design for word processors or control rooms and it deserves similar observational and empirical studies. This paper is a contribution to this larger goal. It focuses upon the role of empathy in a bulletin board medical support group.

## **2. Balancing empathy and factual information**

For many people the only source of communication about a medical problem is their doctor. They may get a second opinion from another physician, although this is not easy in many parts of the world and even if it is, the patient may fear offending the original doctor. For those that have the time and inclination, local support groups provide an opportunity to meet maybe five, 10 or even 20 other people experiencing similar problems. On-line support groups can connect thousands of people, and for each person who posts publicly, there may be many [3] who benefit by lurking or who opt to make private contact via E-mail with a person who has posted. The World Wide Web and on-line medical support groups give patients a way of getting information and support themselves, which in turn enables them to take more control of their own future, even though they need to be aware of the dangers of incorrect or misleading information.

After lurking on medical support groups concerned with back pain, infertility, diabetes, cancer, knee injuries and other orthopedic problems for several months, it became clear to me that similar questions were asked again and again by different people. Sometimes the questions were phrased slightly differently or included additional information but sometimes they were almost identical. Often these questions were raised by newcomers to the group and were then answered by the old-timers. What amazed me was the tolerance of the community. Occasionally, someone would refer the questioner back to a previous communication but there was no evidence of posting acrimonious replies (i.e. flaming) and very little evidence even of frustration.

My initial reaction was to wonder why no one had thought to provide the answers in a

more efficient way — in frequently asked questions (FAQs) files, for example. As I read more, I realized that the nature of the communication was often different than I had first thought — something else was happening. The communication was about much more than just exchanging factual information. It was about identifying and communicating with others experiencing similar problems. These people could identify strongly with the fear, the pain, the inconvenience, the frustrations, and the delights expressed by others who were recovering from an accident, surgery or illness. They were either going through similar experiences or they had been there. They knew what the other person was experiencing and feeling. *Empathy* was the compelling ingredient in many of these conversations. Of course, it is also true that many people want ‘the facts’ about their illness and more efficient ways of providing these would undoubtedly be appreciated. However, both kinds of communication need to be supported — factual and empathic — and balancing the two may be tricky.

It is likely that introducing new structures to support one kind of information exchange will impact the other and could change the nature of the community. Consider, for example, how providing concisely written answers in FAQs may inhibit people from asking related questions in case they are thought unnecessary and a nuisance by others. The presence of FAQs may encourage less tolerance and more abruptness. One can imagine seeing such comments as: “see the FAQs”, or “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” and worse expressions of annoyance. Some systems have this facility and it appears that new users get used to it quickly [4], but we do not know what effect this has on empathy, which is important for medical support groups. Further, formally presented information tends to be thought of as official. This is a serious concern, particularly, if the people supplying the information do not have medical training and may be providing inaccurate or wrong information. Not surprisingly, physicians have legitimate concerns about the use of the WWW for this reason. However, bringing professionals into the community will bring a sense of authority, which will change the nature of communication and may destroy some of the empathy that would otherwise occur between patients. The social ecology of human groups is delicate. Just as in ecosystems of animals and plants, the dynamics of social ecology is such that many variables are inter-related and impact upon one another. Change one and there can be a ripple of change through the whole system in ways that may be unexpected. The dynamics of on-line 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 structure of the community space could have a big impact on the way the community functions.

### **3. Nature of empathy and implications for on-line communities**

Empathy is the ability to identify with and understand another’s situation, feelings and motives. Communicating understanding, sympathy and love requires empathy. Sometimes we observe empathy in others but sometimes it is so embedded in communication that we may not even notice it. Skillful advertisers sell products by using the power of empathy.

Conversely, absence of empathy is easily recognized in real life. Atrocious behavior between people at war, torture, or when parents emotionally detach from children, and the vicious behavior of some divorcing couples are symptoms of lack of empathy. We might ask ourselves if there is an on-line virtual equivalent of such behavior. Although there is no physical component in on-line behavior, extreme cases of flaming in textual communities and stealing and fighting in MUDs and are known to cause distress (see Ref. [5]).

We start to learn empathy from our parents, when only a few months old. Most empathic development occurs during childhood and the rate of learning usually decreases through adulthood [6]. Ability to empathize affects how well we communicate our thoughts and feelings with others, how well we understand others and how comfortable people feel communicating with us. It is at the root of meaningful and deep communication. Understanding the nature of empathy and empathic accuracy — the ability to accurately convey and interpret emotions — is a key concept in psychotherapy [6,7]. It is also central to the notion of ‘emotional intelligence’, described in Ref. [8] as the ability to understand other people; what motivates them, how they work and how to work cooperatively with them.

The literature on empathy in psychotherapy is large and dates back many years. Studies have shown [9], that empathy comes from experience, although partial empathy can come from hearing and understanding the experiences of others. Empathy is how we feel about the world as a result of particular experiences or knowledge, and how we and the experience or knowledge change in the process of us experiencing it. [7] defines empathy as a ‘‘complex psychological inference in which observation, memory, knowledge and reasoning are combined to yield insights into the thoughts and feelings of others’’. Empathy has both cognitive and emotional components, which can be sufficiently powerful to cause spontaneous communication between people and even physiological synchrony. For example, the estrous cycles of college women living together in dormitories are known to synchronize. People with similar backgrounds, such as those belonging to the same family or culture or who share similar experiences tend to show more empathy towards each other than to strangers. So it is likely that there will be strong empathy between people in support groups with a strong and narrowly focused shared interest, particularly if they have similar life styles, as in the ACL community, discussed later. It has been shown [8] that, around 90% of empathy is conveyed through touch, gesture, gaze, voice and posture. So, an important question for research in text-based on-line communities is, how well and in what ways is empathy conveyed via text, which does not have these visual cues, except in the impoverished form of emoticons, such as smilies (e.g.). It is foreseeable that the role of empathy in video-based communication will also become important as video-conferencing across the Internet becomes more prevalent [10,11], but this is not a concern of this study.

Feedback and increased exposure to a situation or person encourage people to build-up empathy and closely associated with this is development of trust. The implications for on-line medical support groups are both good and bad. The benefits of receiving and giving empathy is good but the potential for trust being abused by people posing as medical experts is alarming. The desire by some people to create new or false personae is already well known, especially gender swapping [12,13]. One can imagine instances of people posing as professionals in order to give or, worse still, sell advice. One way to stop this

would be to appoint trustworthy moderators who would lightly review communications before posting but this would have to be done sensitively. The knowledge that messages are being moderated often changes the nature of the communication. For example, in a study of 20 Lotus NOTES databases, each containing more than 100 documents (see Ref. [14]) examined several factors including the role of moderation on communication. Whittaker found that moderation tended to discourage conversations. The conversational threads were shorter, there were more dead-ends. There was also less spontaneity in moderated groups. This finding tends to fly in the face of conventional wisdom (e.g. as in Ref. [13]), which suggests that moderation reduces incidents of flaming and could, therefore, be assumed to encourage empathy. The difference in these two findings can probably be explained by differences in moderating practices. What seems to be agreed is that moderator intervention will change the natural communication.

Research [7] also shows that empathy is used to project forward to understand what a situation would be like in the future. It's a little like a 'what if...' thought experiment. This is key to the success of many support communities on or off-line. Most physicians, and especially surgeons, are extremely busy and have limited time to spend with patients. In addition, it is likely that many physicians cope with pain, sickness, terminal illness and death by partially blocking their empathic feelings. How else could they cope? This argues strongly for bringing people with shared experience together using Internet technology as well as face-to-face meetings. In the medical support groups that I observed, there are people at all stages of recovery and much of the conversation is concerned with 'what to expect next and how it feels'. In a study of on-line support for home-care providers of chronically sick children with cancer, it has been reported [15] that being able to check with other care providers about what to expect in different treatment situations was very important for the parent care providers. Similarly, knowing that they were not alone with their problem was comforting. This is summed up well by a comment from a patient in my study, who said: "we're all in this together, which helps".

#### **4. Related research on on-line behavior**

Little if anything has been written about empathy on-line but much has been written about communities and computer supported social interaction and some of these reports are relevant to this study.

The first, and one of the most famous on-line communities, is the WELL (see Ref. [16]), developed in the early seventies to foster communication between members situated in and around San Francisco. One member of this community [16] describes how he felt so close to people in his on-line community that he had to limit his time on-line in order not to damage his family life. He also recounts how people on the WELL answered his pleas about how to deal with the distressing discovery that a child had ticks. Most moving of all, however, is an account of the support given to a parent of a dying child. Empathy, though not mentioned explicitly, is undoubtedly a significant factor in these stories and the success of the community over the years.

It has been commented [4] that the social construction of on-line communities is greatly facilitated by social and technical affordances. The Zephyr system, developed at MIT, was

created over 8 years ago to support students learning programming. It is like a chat system and carries over 30 000 messages per semester. All users are students; professors are not allowed onto the system. It is also maintained by its' student user population. One such affordance it offers is rapid response time and turn-around of messages. Students get answers to their questions very quickly and because of this fast response from other members of the community, the authors say that there does not seem to be a need for a system memory. It does not matter if the same question is asked again and again. In a study of the general use of E-mail, the authors (see Ref. [17]) point out that in the professional setting that they studied, many e-mail conversations are multi-threaded with several conversations going on at once, information getting lost and the same questions being asked again and again. Another affordance mentioned by Ackerman and Palen is Zephyr's simple interface, which makes it easy to use but, which the authors admit, "is a bit of a paradox" (p. 268). This interface is rudimentary. It consists of either a text-based, teletype interface or a simple graphics interface. However, the interface not only supports collaborative problem solving well, it also enables the users to maintain and organize their electronic social space. One can speculate that, although simple, the functionality and usability are appropriate. Further, it is likely that a group of students learning programming would be able to make almost any system work well. The equivalent design used by foreign language students may not have worked so well because this group probably would not have the necessary computing skills. The important issue is that, the design suits the skills and expectations of the users and supports their communication tasks well, which seems to have been the case in this study.

It has been reported [17] that private communication channels are useful for discussing topics of narrow interest, or of a personal nature or for contentious one-to-one debate. [18] also comment that there are limits to the amount and kind of information that any one individual will make available to the public at large, so private forms of communication are needed. One-to-one communication is also known to be liked by women and girls [19], so making this facility easily available may help to encourage them into on-line communities.

Previous studies [20] report that in HomeNet, an exploratory network encouraged by donation of machines for local community use, the most frequent users were teenage males, who out-numbered teenage females by a ratio of 2:1 and that adult males out-numbered adult females. They found that having children in the house was the strongest predictor of high usage of the technology. Some other findings include the following: social people use the Internet frequently, as did depressed people, time pressures do not seem to affect usage but people who experience a large number of day-to-day problems are low users. Although this study does not address the issue of empathy, it does point out some dimensions that need to be studied in order to characterize on-line communities more accurately, which will be relevant to future studies of on-line support groups.

'Beyond being there' (see Refs. [21,22]) was a project at Bellcore, which examined the relevance that users attached to messages that were posted in short-lived interest groups, which the authors referred to as *ephemeral groups*. The strong focus of these groups and their ephemeral nature make them similar to some empathic groups where a portion of the community recovers from the condition, leaves the group and is replaced by new-comers. On-line support groups also tend to have a strong focus. The authors say that the value of

these virtual communities is very high while they last. This is true for empathic support communities like the one in this study. How else can patients get access to so many other patients, without having to travel and at their own convenience?

## **5. Case study of an empathic support group**

After observing behavior on bulletin boards, Listservs and UseNet groups for over two years, I became intensely interested in one particular discussion group. The following account briefly describes the community, notes some general observations and presents an initial study in which I examine the role of empathy in the postings.

### *5.1. The ACL community*

The anterior cruciate ligament, commonly known as the ACL, is one of four ligaments that holds the patella, femur, tibia and fibula in place. This ligament is a key structure for maintaining the stability of the knee. Without it the knee tends to slip sideways and may give way. This ligament also plays an important role in balance. Tearing or snapping the ACL is a well-known sports injury. It is reported that there are around 20 000 torn ACLs per year among skiers in the USA. It is also suffered by basketball, frisbee and tennis players. Getting this injury is bad news, as it stops or greatly reduces sporting activity for several months or years depending on how well the treatment works. Although the injury is common and not life threatening, it can mean a change of life-style for people intensely and passionately involved in sports, which can be depressing.

There are two basic ways of treating the problem. The patient may undergo surgery to reconstruct the missing ligament. Alternatively the patient can work on strengthening the surrounding muscles to compensate for the missing ligament. This involves an intense program of physical therapy for several months, followed by regular exercises throughout the rest of the person's life. If surgery is chosen, then recovery time varies from person to person but generally takes six to ten months. Reports of pain and discomfort experienced from surgery vary too, from very little to considerable. However, surgery tends to be favored by athletic people because, for most people, it brings nearly full recovery and eventually a return to regular sporting activities.

As might be expected, the choice of treatment is not as straightforward as it might seem and there is considerable debate about what to do. Some factors that need to be considered include, deciding between different versions of the reconstruction if surgery is selected, awareness that people respond differently to treatments and that the degree of recovery varies too. Age, gender, body mass, type of life-style and attitude are also variables. There are many issues to consider in making the choice and then working through the recovery phases.

As with any sickness there is stress, uncertainty, depression, pain and frustration. For some people surgery and rehabilitation are painful, for others being kept away from the sports that they love for several months is frustrating, especially when future life-style is uncertain. Orthopedic surgeons can answer straightforward medical questions but what many people want, is answers to questions like those that follow. What happened to other

patients? How much did it hurt? How does what I am experiencing compare with what you experienced? If I do this, what should I expect?

### 5.2. *Structure of the ACL community space*

The ACL home page is at: <http://www.math.ufl.edu/~sfm/ACL/acl.html>. The Web site has four parts:

- ‘pages’ of information about the structure of knees, the ACL injury, surgery (complete with video) and rehabilitation;
- a bibliography of additional references annotated with comments;
- ACL stories from individuals; and
- Bob’s bulletin board, where people post their comments and questions for others to read and answer.

This paper focuses on the bulletin board (<http://www.cnct.com/~bwillmot/knees/wwwboard/>).

### 5.3. *The bulletin board*

Bob’s bulletin board started in April 1996. The number of postings per day increased from 24 in May 1996, to over 100 in April 1997 and continues to increase. By October 1997 there was an archive of around nine thousand messages. The basic structure of this bulletin board is like many others on The Web. Messages are presented in chronological order unless they are replies to already posted messages. Replies are ordered underneath the messages to which they refer. Indenting is used to indicate replies and sometimes this indenting is two, three or four levels deep indicating replies to replies. Subject headings and the way people express their identity also varies.

The bulletin board is fairly rudimentary, there is no way to search it or order messages, such as by date, topic or sender as in some bulletin boards. Headers indicate the content of a message but this is under user control and there are no posting guidelines, so the accuracy of these user headings for describing the content that follows is highly variable. Some examples of typical headers 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)

Reasonable guesses can be made about the kind of content that might follow but in most cases it is far from obvious. User names vary too. Some people use login names, some use first names, some full names, some just give initials and some give a description.

The gender ratio is very close to two males to one female, which is similar to that reported for general Internet users (see Ref. [1]). When the board started there was a much higher proportion of men and a pilot study from March 1996 of 155 postings showed a gender ratio of 4:1 males:females. The population is partially transient. A large proportion changes as new people suffer the injury and come onto the board and old-timers recover and leave, but there are also members who joined the group many months ago and who



come back occasionally to answer questions. Most of the members are between 20 and 40 years of age but there is a significant minority of older people, a few people in their teens and a few family members posting on behalf of others. Sport tends to be a strong interest shared by most people using this board.

Messages are not regularly monitored but the originator of the board has intervened a few times, mostly to remind people about earlier discussions. This bulletin board is open to anyone, so flaming, spamming and postings of junk mail, aggressive and obscene replies could be expected, but very few messages have been stopped. Although moderation is light it probably ensures a climate in which empathy can develop between members. There is no obvious sign of gender swapping or unusual behavior.

People with a professional interest in the problem tend to identify themselves. For example, one poster advises on choice of knee braces for sports and always refers to himself as “the DonJoy Guy”, with DonJoy being the name of his company. There have also been a few postings from a physical therapist but, up to the time that this study was done, physicians have not appeared on the board. Consequently, almost all the discussion is between people who are suffering the injury and not from experts. The tone of the messages suggests a sense of equality and trust within the group. Communication between members appears to be altruistic and helpful, sometimes cathartic, and often empathic. People want to share their experiences and support each other.

#### 5.4. *A study of communication on the bulletin board*

In order to understand the role of empathy and factual information exchange in this community, we sampled 500 messages from the archive. Five samples, each of 100 consecutive messages were collected at roughly two month intervals over a period of almost one year. We then did a content analysis [23] and developed a taxonomy of five types of comments: *empathic*, *non-empathic*, *question/answer (i.e. factual)*, *personal narrative* and *other* — a catch-all category. Each message was examined holistically and was classified in one category only according to the *overall* tone of the message (see Ref. [24] for additional details).

The taxonomy was first developed in a pilot study of 155 messages. However, when we tested the inter-researcher reliability it was only 66% agreement. After revising the categories we got a high inter-researcher reliability of over 95%. The five categories are:

##### 5.4.1. *Empathic*

These postings had a strong empathic content and echoed the definitions of empathy given by psychotherapists [9,6,7]. People asked for support and gave support. The overall feeling conveyed in these messages was one of mutual understanding and caring developed from shared experience. Examples are:

“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 do my exercises...Thanks for listening.:]”

Hey PMA, You will be fine. Good luck!!! Keep in touch!!

...I'm 11 weeks post-op and doing great so I bet it won't be all that long until you'll be up and comfortable.

#### 5.4.2. Non-empathic

These postings are unsympathetic or non-empathic. We included this category because we have observed these kinds of postings in other on-line communities but, as the results show, none were found in this study.

#### 5.4.3. Question/Answer (i.e. factual)

These postings contained factual questions and answers. Example comment:

... isometrics are a good way to exercise the legs without putting undue stress on the compromised ACL

#### 5.4.4. Personal narrative

These postings contained stories or personal accounts. There is no explicit empathic comment, but the comments in this category are close to being empathic. By providing information about themselves, their circumstances and details about the conditions in which their injury occurred, these posters invite empathy from others without actually asking for it. Examples are:

Well here is my story. ... I am 26 and have been skiing for 11 years with no injuries until now. It all started with the famous last run ... I went for an MRI. ... I'll be writing back with some PT details as they become available.

Later this week I have another doctor's appt. I hope to schedule my surgery for the end of October. I'm nervous but very anxious to be doing post-op PT and walking again. I have clients and friends who have supported me during this time. They have been a real help. ...

#### 5.4.5. Other

These are mainly jokes about physicians and American insurance companies.

Analysis of the 500 postings revealed that 44.8% of the responses were *empathic*, 17.4% were *question/answer* (i.e. *factual*), 32.0% were *personal narrative* and 5.8% *other*. There were no non-empathic responses. Table 1 shows the raw counts and the percentages. Fig. 1

Table 1  
Number and percentages of postings in each category ( $n = 500$ )

Response category	Total number	Percentage of total (%)
Question/answer	87	17.40
Empathic	224	44.80
Personal narrative	160	32.00
Other	29	5.80
Non-empathic	0	0.00
Total	500	100.00

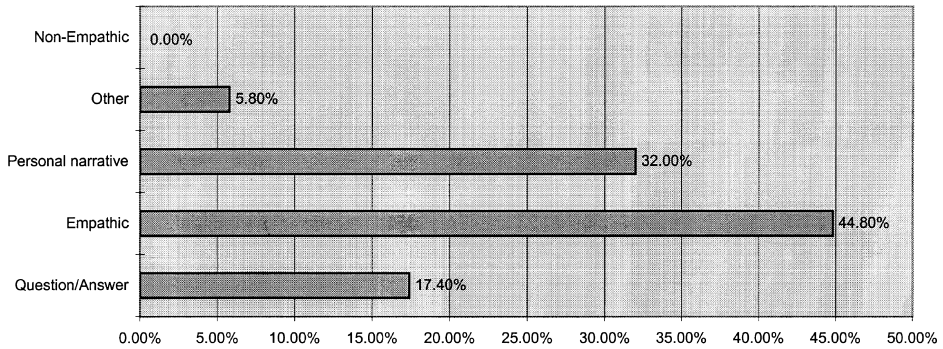


Fig. 1. The percentages of postings in each category ( $n = 500$ ).

shows the percentages graphically. These posts were from 251 individuals as shown in Fig. 2. The maximum number of posts from a single person was 24, from Bob the creator of the board. Almost all of these posts were answers to questions and directions for people to check earlier posts including archived posts for discussions on the same topic.

The remaining 250 people posted 476 messages and of these, 100 messages were posted by two or more people. This distribution suggests that more people are participating than in many on-line communities.

These results suggest that empathic communication is important in this community and analyses of data collected from 100 different discussion groups, which has just begun, suggests that there are many other equally empathic communities on the Internet. We are also finding that there seem to be gender differences associated with the way women and men express empathy and communicate about medical issues [24].

## 6. Discussion — the way forward

Empathy is a fundamental part of human communication but until now it has been rarely discussed in computer supported co-operative work (CSCW) and computer mediated communication (CMC) research. There are several possible explanations for this. The

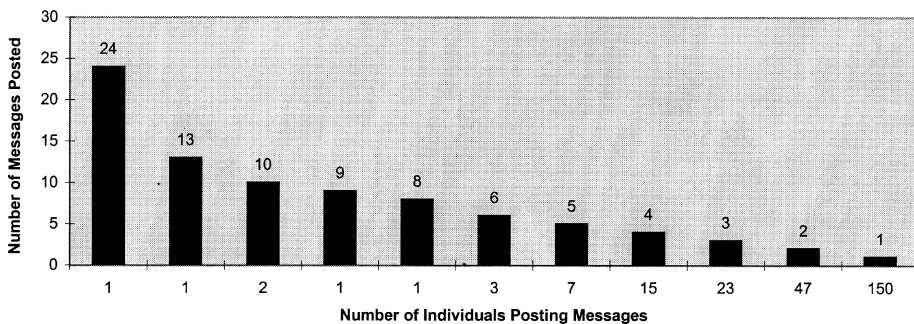


Fig. 2. Number of responses per individual ( $n = 500$ ).

first is that most of this research has examined communication in formal work situations where empathy is present but is subtle compared with personal, informal communication. The second reason is that the researchers involved in CSCW and CMC research are not part of the psychotherapy community, medical or social carers, in which empathy is regularly discussed. The third reason is that it has taken a while for a sufficiently large number of empathic communities, like the ACL community, to develop on The Web and be noticed.

This study of the ACL communities' messages suggests that empathy has an important role in the communication of this community. A research agenda is now needed for investigating the role of empathy in computer mediated communication of all types. The first part of this agenda is in progress and involves investigating a range of different communities. The aim is to develop a taxonomy of on-line communities, characterized along different dimensions, so that empathy in communities in different parts of the taxonomy can be examined. Some of the dimensions that we will investigate include: number of members, gender, age, topics of interest (i.e. focus of the group), frequency of posting, whether the list is moderated and if so, how this is done etc. We will categorize the empathic communication content of a sample of posts and look to see if there is a correlation with some of these attributes. The second part of the research agenda, for which the early work is needed, is to examine design solutions to support empathic communication, so that it can co-exist well with factual communication exchanges. As well as design solutions, improved protocols for interaction and moderation will be examined. The following suggestions provide a base-line for this work.

### *6.1. Making private communication via email easy*

Like most bulletin boards, e-mail addresses are not easily available so contacting individuals for private communication is not encouraged. By facilitating private communication empathy might be fostered. However, people's privacy also needs to be protected. Further, too much individual posting would take away from the board. Other problems might also occur. For example, a person may wish to send a private note and inadvertently send it to the group as can happen with some listservs.

### *6.2. Better interaction protocols*

One way of making it easier for people to find posts on topics of particular interest is by encouraging careful and meaningful selection of headings for messages. Some lists provide advice on how to present postings. This alleviates but does not completely solve the problem of finding specific information.

### *6.3. Skillful moderation*

It is likely that empathy will be encouraged by careful moderation of messages. In addition, this may be important for dealing with large numbers of people on a single bulletin board. This issue of scalability will have to be addressed as more and more people become regular Internet users. Moderators will be needed to suggest fragmenting the

group for discussions of different topics. However, care will be needed to avoid the extreme fragmentation which has been reported [14].

#### *6.4. Allowing personal book-marking within a bulletin board*

This would enable people to collect information that is specifically relevant to their own personal needs and to keep track of people with similar attitudes or conditions to themselves.

#### *6.5. Techniques for supporting searching*

Research on *recommender* systems suggests that these systems may be useful in this context. Recommender systems are similar to collaborative filtering, but differ in that they may not explicitly collaborate with recipients (refer to Ref. [25]). The term recommender system is a broader term, which includes collaborative filtering systems. Many of these systems enable users to enter their preferences directly, in addition to the system finding them by tracking past user behavior. Using such systems, it might be possible to provide details of posts of interest to users. Users could then decide whether or not they want to follow-up on the recommendations. This could happen in several ways. Users could specify direct requests. For example, a user might request to be notified of posts that discuss the outcomes of a particular surgical procedure in people over forty years of age. The system could also track that a person has accessed posts with a particular term in the heading, and make the person aware of other posts in the archives, which discuss the same topic. People could also provide demographic information about themselves and from this be directed to people of similar age, physique and lifestyle etc. to themselves. Ensuring privacy would be an important issue. GroupLens [26] was designed to provide these kinds of facilities for Usenet news readers. In common with many bulletin boards the volume of traffic in Usenet news is high and only a small amount of it is likely to be useful to most users. A pilot study indicated that GroupLens was a useful service even though it was difficult to get adequate ratings upon which to base searches because of the small number of articles read by each user.

Many techniques that already exist to support information searching, such as forms for users to provide details about themselves, could be employed to support empathy. For example, just after having the injury, most people want to find out more about the broken ACL; how it will affect their life; how it can be treated; and what the treatment involves. At this stage, many people want to make contact with others similar to themselves in terms of age, gender, life-style, body mass and so on. Including a simple form for new-comers to complete, so that the information can be added to a database, which can be searched, would enable people to find each other more easily. Later on in the injury, communication tends to become more empathic and less driven by a need to find information. Techniques like those used in the FilmFinder [27] could also be used to enable participants to visualize characteristics of community members and to locate specific individuals. For example, it would be possible to find women over the age of forty years who have not had surgery and then identify specific individuals. What makes the use of these tools different in this context, is the need for designers to be aware that a delicate balance may exist between supporting empathy and efficient information retrieval.

Designing to support efficiency may be detrimental to supporting empathy, because it may discourage people from answering questions that have already been raised and may encourage aggressive responses to those that ask them. However, understanding a medical problem, even a serious problem, can be comforting as it enables patients to feel in control of their own lives (see Ref. [15]). This raises another issue, which is ‘what is the relationship of information provided by discussion groups to that provided on web pages?’

## **7. Conclusion**

The important message from this work is that on-line communities are changing and that empathy, as well as factual information exchange, is important. By listening to this message and by designing tools and community spaces that empower medical support groups, like the ACL community, we can improve on-line support for thousands of people. However, care is needed to balance designs so that they support both factual and empathic communication. For this to happen more research is needed, which builds on this study.

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## **References**

- [1] J. Pitkow, C. Kehoe, GVU’s WWW User Surveys, [http://www.cc.gatech.edu/gvu/user\\_surveys/survey-10-1996/](http://www.cc.gatech.edu/gvu/user_surveys/survey-10-1996/).
- [2] R.H. Anderson, T.K. Bikson, S.A. Law, B.M. Mitchell, Universal Access to E-mail: Feasibility and Societal Implications, RAND, Santa Monica, CA, 1995.
- [3] J.M. Carroll, M.B. Rosson, Developing the Blacksberg village, *Communications of the ACM* 39 (11) (1996) 69–74.
- [4] M.S. Ackerman, L. Palen, The Zephyr help instance: Promoting ongoing activity in a CSCW system, in: *Proceedings of CHI’96*, 1996, pp. 268–275.
- [5] P. Curtis, MUDding: Social Phenomena in Text-Based Virtual Realities, in: S. Kiesler (Ed.) *Culture of the Internet*, Lawrence Erlbaum, NJ, 1997.
- [6] R.H. Etchegoyen, *The Fundamentals of Psychoanalytic Technique*, Karnac Books, London, 1991.
- [7] W. Ickes (Ed.), *Empathic Accuracy*, The Guildford Press, New York, 1997.
- [8] G. Goleman, *Emotional Intelligence*, Bantam Books, New York, 1995.
- [9] A. Comfort, *Reality and empathy: Physics Mind and Science in the 21st Century*, State University of New York Press, Albany, 1984, p. 18.
- [10] W.H. Gates, *The Road Ahead*, Viking, New York, 1995.
- [11] N. Negroponte, *Being Digital*, Hodder and Stoughton, London, 1995.
- [12] S. Turkle, *Life on the Screen*, Simon and Schuster, New York, 1995.
- [13] L. Sproull, S. Kiesler, *Connections: New Ways of Working in the Networked Organization*, MIT Press, Cambridge, MA, 1991.

- [14] S. Whittaker, Talking to Strangers: An evaluation for the factors affecting electronic collaboration, in: Proceedings of CSCW'96, Conference on Computer-Supported Cooperative Work, 1996, pp. 409–418.
- [15] L. Tetzlaff, Consumer Informatics in Chronic Illness, *Journal of the American Medical Informatics Association* 4 (4) (1997) 285–299.
- [16] H. Rheingold, *The Virtual Community*, Addison Wesley, Reading, MA, 1993.
- [17] S. Whittaker, C. Sidner, E-mail overload: exploring personal information management of E-mail, Proceedings of CHI'96, 1996, 276–283.
- [18] H. Kautz, B. Selman, M. Shah, Referral Web: combining social networks and collaborative filtering, *Communications of the ACM* 40 (3) (1997) 63–65.
- [19] D. Tannen, *Talking from 9 to 5*, William Morrow and Company, New York, 1994.
- [20] R. Kraut, W. Scherlis, T. Mukhopdhyay, J. Manning, S. Kiesler, HomeNet: A field trial of residential Internet services, in: Proceedings of CHI'96, 1996, pp. 284–291.
- [21] L. Brothers, J. Hollan, J. Nielsen, S. Stornetta, S. Abney, G. Furnas, M. Littman, Supporting informal communication via ephemeral interest groups, in: Proceedings of CSCW'92, Conference on Computer-Supported Cooperative Work, 1992, pp. 84–90.
- [22] J. Hollan, S. Stornetta, Beyond being there, in: Proceedings of CHI'92, 1992, pp. 119–125.
- [23] C. Robson, *Real World Research*, Blackwell, Oxford and Cambridge, 1993.
- [24] J. Preece (1997), *Offering Support and Sharing Information: A Study of Empathy in a Bulletin Board Community* (Draft available from the author).
- [25] P. Resnick, H.R. Varian., Recommender Systems, *Communications of the ACM* 40 (3) (1997) 56–58.
- [26] J.A. Konstan, B.N. Miller, D.M. Maltz, J.L. Herlocker, L.R. Gordon, J. Rieddl, GroupLens: applying collaborative filtering to UseNet News, *Communications of the ACM* 40 (30) (1997) 77–87.
- [27] C. Ahlberg, B. Shneiderman, Visual information seeking: Tight coupling of dynamic query filters with starfields displays, in: Proceedings of CHI'94, 1994, pp. 313–317.