

## **An Ethnographic Study of an Online Health Support Community**

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### **Introduction**

This paper describes a study of a thriving online health support community (Bob's WWWBoard) that utilized an ethnographic approach. The goal of the study was to increase understanding about the role an online health community plays in the lives of its members and to document social interaction within one such community. The study seeks to inform the work of online community developers and health care professionals as they seek to establish more effective ways of meeting the needs of individuals with health concerns. It is based upon the theories of ethnographic research (Baym, 2000; Fetterman, 1998; Hine, 2000; Nardi, 1997; Walcott, 1999); sociability and usability from human-computer interaction (Jacko, Sears & Borella, 2000; Larson & Czerwinski, 1998; Lynch & Horton, 1999; Nielsen, 1998; Preece, 2000b; Shneiderman, 1998); on social network analysis from sociology (Wellman & Frank, 2001; Garton, Haythornwaite & Wellman, 1999); and, on group membership roles (Benne & Sheats, 1948) and Interaction Process Analysis (Bales, 1951, 1958) from social psychology.

{new para?} The study takes a multi-level research approach because the complex nature of the online textual environment in which the community is embedded requires a combination of investigative tools in order to develop a deep understanding of the factors that affect the community. An ethnographic approach was selected as the guiding framework for the study because of its focus on telling the story of a community through the words of its members. The ethnographic approach is "concerned with people's lived experiences and is well suited for finding the meaning people place on the events, processes and structures of their lives" (van Manen, 1977). This approach accepts and documents multiple realities, thus guarding against the presentations of a stereotype of the online community (Fetterman, 1998).

The study's goals and related research questions are:

- **Goal One: To understand the role of the online community in the lives of its participants.** Research Questions: What role does the online community play in the life of its participants? How does their participation affect their daily life?
- **Goal Two: To gain an in-depth knowledge of the culture of the Kneeboard.** Research Questions: What are the norms, values, beliefs, and patterns of behavior of participants on the Kneeboard? How do participants convey their attitudes, beliefs and values to one another? What are the purposes and goals of the bulletin board and how are they expressed?
- **Goal Three: To identify the dynamics of social interaction on the Kneeboard.** Research Questions: How do individuals interact on the bulletin board? What are the effects of the online textual environment on group dynamics? What are the patterns of social attractions among participants? What membership roles do individuals play? What are the similarities between self-help group interaction in **face-to-face** groups and on the Kneeboard?
- **Goal Four: To inform the software design, development, and management of online health communities.** Research Question: What are the usability and sociability issues that affect the Kneeboard, and what are their effects?

### **The Study**

The study took a broad fieldwork approach guided by the ethnographic research techniques of observation, interviewing, and archival research (Crabtree & Miller, 1992; Fetterman, 1998; LeCompte & Schensul, 1999; Miles & Huberman, 1994; Wolcott, 1999). The ethnographic research approach focuses on the ways all aspects of a culture are related (Nardi, 1997). This approach was adapted for use in a textual environment on the Internet following the examples of Baym (1997, 2000), Hine (2000), and Silver (1999). The study consists of four research phases as presented in Table 1.1.

Table 1.1 Research Phases, Activities, and Aspects of the Online Community that are Examined

Research Phase	Research Activity	Aspects of the online community that are examined
Phase I	The researcher observes the Kneeboard for 2 and 1/2 years	Provides an in-depth knowledge of the activities, members, and contents of the online community
Phase II	Description of the Kneeboard and its Internet Site Analyze the Kneeboard using sociability and usability heuristics	Examines and evaluate the virtual environment of the community
Phase III	Analyze the messages posted to the Kneeboard November 11-17, 2002 using: a) Social Network Analysis b) Group Membership Roles c) Interaction Process Analysis	Examines patterns of communication, interaction, and group dynamics on the Kneeboard
Phase IV	Interviews with Kneeboard members	Examines the meaning of the online community and the role it plays in the lives of its members. The data also provides a method for verifying findings from the other phases of the research

Each phase of the research examines different aspects of the social environment and the interactions within the community. By combining a long-term immersion in the community as an observer with systematic data collection, analysis, cross checking and triangulation of observations and data, a thick and rich description of the culture, norms, and dynamic processes of the Kneeboard emerged.

### Highlights of the Study

The Kneeboard is a very successful online community by all standards of measurement: the high levels of viewing and posting activity over the seven years of its existence, the low levels of

aggressive and hostile behavior expressed, the common expression of empathy and support that characterize the community, and the comments of community members that reflect their beliefs that the community is a positive and valuable resource. Yet, the Kneeboard did not meet some of the usability best practice criteria and many of the sociability criteria established by online community designers and developers (Kim, 1998, 2000; Preece & Maloney-Krichmar, 2002; Preece, Rogers, & Sharp, 2002). This has important implications for designers and developers of online communities that will be discussed in the following sections of this chapter.

There are several major factors that appear to contribute to the success of the Kneeboard community. The **narrow focus** of the community helps maintain feelings of cohesion within the group. Communication between members is largely limited to knee injuries and treatments issues. In general, members do not engage in discussions of political and religious beliefs, and personal problems; therefore, they only relate within a very narrow range, which limits tensions that might arise over differences in personal beliefs and practices. In addition, the online asynchronous environment allows members to tightly manage their presentation of self. They reported that they read messages and respond at their leisure, rewriting and editing messages to be sure they convey exactly what they intend. As one Kneeboard member said: “in real life I don't have the same opportunity to write and re-write my responses to make sure they address questions, issues and emotions and (as much as possible) don't put the reader on the defensive” (Barbara, 6/28/02). Members post profiles and photographs that represent them as they want to be viewed. With few exceptions, members do not interact offline, this limits the types of problems that might occur if they had to relate face-to-face.

The **diversity** within the membership, the diversity of experiences, and the wide range of information that is available in the community is viewed as valuable social capital by community members and is an important factor in the success of the community (Putnam, 1995). Mark explains the value of diversity:

*“it definitely is/was a group that could tolerate discussions to the nth detail about the ins and outs of the knee deficiencies, surgery, recovery process, etc. It was also a very important source of information. Having one person respond was generally not that helpful but when you would get many responses or others would ask similar questions and there would be*

*additional responses to read, the individual quickly ramped up on the ACL educational curve” (6/26/02).*

In addition to the information provide by community members, the Kneeboard’s Knee Injury Articles Library provides an important source of information. Peter explains: *“The ‘information’ aspect was tremendous because the group either had a library that you could reference, or there were regulars who maintained their own informational websites. Plus people were always pointing to some article on knees. It was a nice form of one-stop shopping” (10/21/02).*

The convenience and flexibility of **access** to the community twenty-four hours a day, seven days a week (24/7) is another feature that contributes to the success of the community. The asynchronous bulletin board environment and the Internet makes it possible for people from disperse geographic areas and time zones to personally interact with others who were going through similar experiences. Finally, the caring, empathic and humorous nature of the community is a major factor in its success. One member explains: *“It is supportive but doesn't encourage moaning. It deals with people in an encouraging way and the posts tend to have the same positive tone” (Lauren, 10/17/01).*

The factors that contribute to the success of the community are facilitated by the use of a bulletin board, embedded in the Internet. The ability to log on to the community at will, select which messages to read, post when there is a need or an interest in doing so, edit, store and retrieve messages, move in and out of the community with ease, and contribute to the community at a level that is comfortable and compatible with members’ lives are all mentioned by members as valuable and attractive characteristics of the Kneeboard. These characteristics are enabled by the technical environment. Kneeboard members like the asynchronous bulletin board environment. They were vocal about not wanting or needing advanced or enhanced technical environments (i.e. chat room, 3-D graphical interface) (Abrams, 2003; Maloney-Krichmar, 2002). The Kneeboard community seems to function so successfully because of the intersection of the needs of its members, the technical environment, the cycle of injury/treatment/recovery associated with the knee injuries, and the established norms and values of the community. For example, Holly said the group works for her because: *“I think you are still somewhat anonymous, but everyone*

*is there to support you, you can access it anytime you want to, you can ask questions and not feel stupid, sometimes real live encounters can be nerve-racking, rather than online where you can't be nervous" (7/20/02).*

### Patterns of Participation

There are patterns of participation on the Kneeboard that contribute to the success of the community. At any point in time, the community is composed of: 1) key community members who post messages on a regular basis over long periods of time; 2) community members who are highly active for a period of time; 3) community members whose activity levels are less intense over long and short periods of time; 4) lurkers, and 5) newcomers. The narrow focus of the Kneeboard means that the communication is always related to one topic—the knee. The narrow focus of the messages and the presence of key community members and members who are highly active help provide a sense of continuity and stability within the community. This fosters a feeling of sameness and consistency that encourages cooperative behavior and the development of strong feelings of closeness between members. The constant influx of new members provides a sense of freshness to the community and provides new sources of social capital that contribute to the continued success of the community. This social interaction provides a basis for the socio-cultural context in which the Kneeboard operates.

There is considerable debate among those studying online communities about the role of lurkers. Some researchers, like Kollock and Smith (1996) describe lurkers as free-riders, individuals who benefit from the social capital of the community, but do not contribute to the community. However, Nonnecke (2000) contends that lurkers are not free-riders, but are non participating members of the community who choose not to post for a variety of reasons. In relationship to the Kneeboard, one of the major concerns of members is losing access to the community because of server break-downs. If, as virtual Bob indicates, there are 100 lurkers for every active Kneeboard member, the fact that lurkers are not posting messages actually contributes to the success of the community. If everyone who logs on to the Kneeboard posts messages, it would present a scaling problem and have serious implications for the stability of the technical environment of the community. In addition, lurking permits newcomers to become familiar with the community and its resources before they begin participating. This reduces the

potentially large number of newcomer questions that could become too repetitive and have a negative effect on social interaction.

### Social Interaction and Community Norms

The study reveals that a positive aspect of the textual, bulletin board environment of the Kneeboard is that it provides a permanent record of community interaction. Anyone can read, retrieve and search the messages posted to the Kneeboard for the past two years. These written records of social interaction are visible to anyone who logs on to the Kneeboard and they reflect the roles that members play and the social interaction among community members. This is one of the ways that the roles and interaction revealed in the messages become standards of behavior within the community.

The dominant group membership roles played on the Kneeboard are *giving* and *seeking information* and *encouraging others*. As a consequence of the dominant group membership roles, the primary forms of social interaction on the Kneeboard are *giving information*, *showing solidarity*, and *giving and seeking opinions*. These roles and forms of interaction serve as powerful examples of how a member should relate to and interact with other members of the community, and what membership roles and types of interaction are rewarded and valued. In addition, the ability to read the exchanges between community members on the bulletin board means that newcomers can experience and evaluate the community before they chose to become active. This study provides evidence that the positive and therapeutic value of being helped and helping others reinforces the desire to play roles that support the community. The norm of reciprocal helping (Jacobs & Goodman, 1989) has been well documented in face-to-face self help groups as well (Forsyth, 1999).

### Effects of Membership in the Online Community on Members' Offline Lives

Findings of the study indicate that Kneeboard members believe that their membership in the community improves their offline lives in a number of significant ways. They feel that it helps their relationships with family and friends because the community provides a unique source of support during the knee injury and treatment period. A community member explains: "*I became totally focused on my knee for several months. It was literally all I thought about. I was*

*thinking about recovery, exercises, the pain, icing, would I ever be normal - all the time. This gets very boring for the other people in your life”* (Mary, 5/13/02). Furthermore, Kneeboard members state that their family members and friends do not really understand how debilitating, painful, and anxiety-provoking a knee injury is. Sandi said: *“Family is there for you, but they tire quickly of the situation and don't understand that our surgeries can take a year or longer to heal from”* (10/20/02). On the Kneeboard, members found people who understood and helped them with information and support through a very difficult period in their lives.

Many community members expressed that the information they received on the Kneeboard improved their medical care and treatment. They were able to go to their physicians armed with information about treatment options and discuss them intelligently. They were able to assess the quality of the care they were receiving compared to other Kneeboard members and in some instances seek second opinions. Some community members located doctors in their area based upon recommendations from Kneeboard members. Jennifer said: *“Initially, the kneeboard was a huge source of information directly from people who have been through this injury. Like I said, I had no idea what was going on with this injury, and the physicians don't always have time to sit there and explain every little detail. In addition, I didn't know what questions to ask either”* (10/22/02).

Kneeboard members reported that participation in the community reduces the anxiety, depression, and isolation that often accompany the long recovery from knee injuries and treatments. Anna describes the way the Kneeboard helps members cope: {is this a quote?}

*“It's also, for many of the board members, the first time they've experienced a major, incapacitating injury, and they a) don't know what to expect, b) are exasperated over the long recovery time, c) depressed about their newly limited mobility, d) scared about the surgery and recovery. So, while going through the reconstruction/rehabilitation process, people seek information, advice, encouragement, compare notes on progress, etc. over a fairly long period of time, thus establishing themselves as contributing members of the community, which feels good emotionally at a time when not much else feels good emotionally.”* (10/17/02).

Membership in the Kneeboard enhances community members' sense of self-esteem by providing the opportunity to help others at a time when their activities in their offline lives may be curtailed due to their injury and they may be more dependent on others for support. John, who manages the Knee Library, is a major contributor in the community. He explains how helping others makes him feel: *"I also enjoy answering questions on topics I am intimately familiar with . . . It makes me happy when, as a result of my efforts, someone is better-prepared to deal with a knee problem"* (7/24/02).

Another interesting finding of the study is that while community members form strong relationships and attachments with other Kneeboard members, they report that they do not have enough common ground (outside the knee injury) to establish strong offline relationships. Some members reported meeting Kneeboard buddies off-line. Mark describes his offline meetings with Kneeboard members: *"The other thing is that even when I met some of the people, there was limited things to talk about once you got past the introductions and knee talk...It was an interesting experience and that's about it!"* (10/17/02). Although, this finding is highly influenced by the geographic dispersion of the online community, some members keep in touch, via e-mail, with persons they meet on the Kneeboard. Sarah talks about friendships she formed on the Kneeboard: *"It's been nearly 3 years since the injury and at some point it is time to "move on". I do keep in touch via e-mail with 2 individuals from the kneeboard. These are 2 people I will not likely meet face to face, however through our mutual experience, I feel I know them"* (10/17/02).

### Weaknesses of the Online Community

Kneeboard members were very positive about their membership in the community. The Kneeboard Administrator, virtual Bob, who works for a company that hosts online communities, indicates that the Kneeboard is their most successful community (11/11/02). However, when asked about weaknesses of the community, Kneeboard members attest that the major weakness of the online community was that, at times, the technology fails. Members indicate that the loss of communication with the community, especially during the early stages of an injury or recovery from an operation, is extremely frustrating. They compare it to being denied something

to which one is addicted. Mary explains: *“I was completely addicted to the board from the time of the injury [spring 1998] to about August of that year”* (11/3/02).

The low bandwidth technical requirements to access the community make it widely available to a variety of people, from many countries, with basic computer equipment and an Internet connection. Some of the minor areas of concern on the Kneeboard are related to the international membership of the community. For example, differences in language usage between English speaking countries occasionally cause misunderstandings. On occasion, there is a need for translation of U.K. or Canadian English to U.S. English. While these problems are not serious, a more important issue was raised by Lauren:

*“However there is a problem when you access this info from the board but cannot match this with local provision. This is certainly a problem in the UK and also in the US for more complicated injuries. In the end I accepted that the treatment that I was getting was not perfect, but it was the best that I could get locally and that counted for a lot. I’m sure with some of the cancer boards this could be quite a problem.”* (7/15/02).

Members become aware of differences in medical treatment options not only from country to county, but often between rural and urban areas. In addition, there have been messages posted to the Kneeboard discussing insurance plans and the cost of the various treatment options. The researcher once witnessed Kneeboard members trying to help a person without medical insurance find a way to secure funds to have an operation. While the Kneeboard addresses the digital divide through low band with technology, it reveals another type of divide—economic and medical—which causes members frustration. It is interesting to speculate on the implications of the fact that these frustrations occurred between persons living in industrialized English speaking countries. How would an online health community composed of persons from a wider variety of countries handle the problems of economical and medical divides?

Many medical associations and physicians caution people to be careful about the information they receive online (Preece, 2000b). They advise people against following any suggestions they receive online without consulting with their doctor(s). The medical community is concerned

about people being misled in ways that may affect their health negatively. Some Kneeboard members reported that their doctors were concerned about the quality of the information they might receive on the Kneeboard. However, others reported that their doctors encouraged them to go online and find out as much as they could about their condition. As has been described previously, many Kneeboard members reported feeling empowered to interact with their doctors in more effective ways thanks to the information they received from the community. Furthermore, they received practical advice about how to handle small problems like swelling, or discomfort during rehabilitation, or using braces, without having to bother their doctors. Yet, while the Kneeboard members were able to describe a problem and receive feedback from community members about the possible causes and seriousness of the problem, the researcher observed many instances in which a response to a message recommended that the person contact their doctor because the problem sounded serious.

The fact that that one has to judge carefully the quality and validity of information provided by community members is described by some members as a weakness of the community. Newcomers are frequently cautioned to consult with their doctors or read articles in the Kneeboard Library before making any decisions based on information received on the Kneeboard. The presence of the Kneeboard Library serves as a counter balance to information provided by participants on the message board. Its presence on the Web site strengthens the reputation of the Kneeboard for providing access to quality information.

## **Discussion**

The study consists of two and one-half years of observation of the Kneeboard. However, only one week of messages was analyzed in-depth. This analysis provides a snapshot of the social network, roles that community members play, and of the social interaction on the Kneeboard. The findings may be limited because variations in the number of message posted may occur in relationship to the seasons of the year (e. g. interaction on the Kneeboard may be affected by ski season, football season, and outdoor soccer season) as a higher number of people may be online in seasons associated with increased risk of knee injuries. But the number of members who post in any one-week may vary greatly. These differences in activity on the Kneeboard from week-to-week, limit the findings. However, the findings concerning group membership roles and

interaction process analysis are similar to patterns reflected in research on self-help and task oriented offline groups (Brown, 2000; Forsyth, 1999; Goodman & Jacobs, 1994; Jacobs & Goodman, 1989). These offline groups show membership role differentiation and patterns of social interaction that focus on attaining the goals of the group (task orientation) and managing the socioemotional issues that arise in groups. In general, in offline groups, about 70% of the activity is related to attainment of the goals of the group and 25% related to maintaining social relationships within the group. The remaining 5% of roles and interaction are individualistic in nature (Bales, 1958; Brown, 2000; Sampson & Marthas, 1990). The findings of the study demonstrate that group membership roles and social interaction patterns closely resemble those of offline groups. In addition, triangulation with the interview data helps establish the confirmability of the findings. The analysis of activity on the Kneeboard over longer periods of time and in other types of online communities can strengthen the understanding of the effects of the online environment on the roles that group members play, forms of social interaction and online group dynamics.

There are several groups that belong to the social networks of Kneeboard members who were not addressed in the study. Their opinions, beliefs, and knowledge could contribute to a deeper understanding of the role of an online community in the lives of its members and should be explored in future research. These groups include:

- Lurkers - In any week on the Kneeboard, the ratio of lurkers to posters is 100:1 (virtual Bob, 11/11/02). These non-participating members have an impact on the community. For example, virtual Bob indicated in an e-mail November 11, 2002 that: "*The Kneeboard's compounding traffic continues to outgrow each server platform we put it on - even with customized/optimized BBS software.*" Server breakdowns and other technical problems are greatly affected by the number of persons who access the community daily. Scaling issues related to lurkers and the effects on the community of making the presence of lurkers more visible are areas of research that deserve more attention.
- Physicians and physical therapists are linked to Kneeboard members; it would be interesting to find out their opinions about the positive and negative aspects of working with patients who are active members of an online health community. In addition, it

would be useful to work with medical professionals to assess the effects of participation in an online health community on the course of an illness and/or recovery from an injury. The therapeutic value of face-to-face patient support groups has been established (Forsyth, 1999; Sampson & Marthas, 1990); therefore, an important research agenda would be to further document the therapeutic value of online health support communities, the types of online communities that best provide therapeutic support, roles for health care professionals in online health support communities, and ways to assure that the information provided by these communities are accurate and have positive benefits for members of the community.

- Family members of Kneeboard members could be interviewed to obtain their ideas on the effect of the online community on their relationships. Kneeboard members reported that their involvement in the community helped their families because it provided an outlet for the tension associated with the injury. It would be interesting to see if family members feel the same way about the role of the Kneeboard in reducing tension and worry. The opinions and experiences of family members about the Kneeboard would make a valuable contribution to understanding the family dynamics during the injury/treatment/recovery period and should be considered for future research.

Finally, issues related to the digital divide are not explored by this study. There is a need for research to determine if the type of support provided by the Kneeboard for its members would be effective with people from all educational and social backgrounds. In addition, research on how to extend the benefits of online communication related to health issues to groups who are underserved or poorly served by the health care systems must be explored.

## **Conclusion**

In *Supporting Community and Building Social Capital*, Preece (2002) states: “*Developing online community requires a deep understanding of social interaction and the mediating effects of technology.*” This study contributes to a deeper understanding of online social interaction and the effects of technology by examining one online health community, Bob’s ACL WWWBoard (the Kneeboard). The study addressed the relationship between community members’ on and off-line lives, provided a deeper understanding of online group dynamics, and broadened the

understanding of the effects of issues related to usability and sociability on online communities. The findings of this study provide information that will help health care professionals and online health community designers and developers to build thriving online communities that improve the lives of individuals who are dealing with illness, disease, injuries, and health concerns.

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