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The Online Patient Meeting

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Introduction

In the past decade, many medical institutions have begun to use patient meetings for education and social support. These innovative practices have developed most successfully in the treatment of cancer. A considerable body of research indicates that these are useful strategies for dealing with severe illnesses of all types.

Today we are seeing a further development of the idea of the patient meeting: online discussions among patients, sometimes with the participation of physicians, on the Internet and other computer networks. These discussions are proliferating rapidly now, offering patients new ways of interacting as well as access to rich information resources. The recent history of networking suggests that we should expect online patient meetings to become a mass phenomenon in the coming years.

It is therefore a matter of some interest what kind of communication flows over these new channels. This paper will explore key questions in the evaluation of online patient meetings. I must emphasize the word "explore" as we are only at the beginning of experience with these groups. It will be some time before there are enough research findings to answer our questions with confidence. However, a first glance at these activities is encouraging: online patient meetings appear to reproduce many of the beneficial effects of face to face meetings, while adding some new and interesting possibilities.

Computer Mediated Communications

Let me begin with a few words about the online environment itself. Computer mediated communications, called CMC for short, includes email, a form of private messaging resembling regular mail, and various forms of public messaging that resemble group meetings. Typically, texts typed by participants at their own computer terminals are transmitted over phone lines to a central computer where they are classified, stored, and eventually delivered. Participants can sign on at times of their own convenience, using the central computer as a meeting place for an asynchronous conversation that may last weeks, months, or years.

Contrary to the commonplace expectation that anything involving computers must be analytic and impersonal, quite complex social interactions take shape on computer networks. Users act "as if" they were participating in one or another familiar face to face situation. They introduce conventions analogous to those which prevail in everyday settings. Although only writing is transmitted, individuals manage to express their feelings and thoughts with remarkable success. Any type of primarily verbal activity can be mediated by computer.

While researchers and employees of large corporations have been aware of this new type of electronic communication for some fifteen years, domestic applications have lagged behind everywhere except in France. Only in the last few years, with the explosive growth of the Internet, has the general public shown much interest in CMC. Today the largest online services, such as CompuServe and America Online have millions of subscribers and are linked to the Internet with its tens of millions of users around the world.

It seems clear that we are dealing with a change in the communicative environment as basic as the telephone. The most important difference between that earlier innovation and this new one is that here for the first time we have the possibility of electronic mediation of small group interaction. It is this unique property of CMC that promises interesting applications to patient education and social support.

An Early Study

In 1990 a study was conducted on the effectiveness of a computer network placed at the disposal of patients with AIDS in the Cleveland area. Called ComputerLink, this network was intended to supplement the educational activities of nursing staff and promote patient interaction. Twenty-six patients were given terminals for the study, which lasted six months.

The project showed that ordinary patients, without prior computer experience, could use the equipment and gain benefit from access to a network. The twenty-six subjects accessed the system over 8000 times in six months. Over half signed on most days, and most appear to have made significant use of the system. Judging from the comments of four patients selected as typical, they found the network very valuable.

What lay behind this positive evaluation? A glance at usage patterns explains a lot. The system offered three functions, communication, information in the form of short summaries, and decision support exercises. The first of these was used about 10 times as much as the other two. Private email was the most popular activity online with reading in the public message forum coming in second. Those who posted messages in the forum were in some sense performing for the majority of passive spectators. This pattern is consistent with other experiences with CMC in voluntary groups.

The statistics indicate that what most patients found most useful was simply the opportunity to communicate with each other. However, the interviews with the four selected patients shows considerable interest in the information functions as well even though they were consulted less frequently. Evidently, information as well as communication is in short supply in this patient community, and any additional channel is appreciated.

Two Contemporary Networks

The authors of the ComputerLink study had a relatively simple job of evaluation compared with the situation today. In 1990 it was necessary to create a network from scratch to learn about its potential. The initiative was with professionals who recruited participants and designed the system to deliver information to evaluators. Even though they did not read the private mail exchanged on the network, the researchers could at

least count the number of messages, and make other quantitative measures. Hence all the statistics available for the study.

Today we are dealing with an entirely different situation. Networks now spring up spontaneously or at the initiative of a few individuals on vast public systems where participants seek out activities of interest on their own. It is much more difficult to gather information, however transcripts of interactions can be printed out and studied. Here are some observations on two ongoing networks focused on ALS and other neurologic diseases.

ALS Digest

The [ALS Digest](#) is a kind of online journal put together by Bob Broedel of Tallahassee, Florida, and published on the Internet. In the past year it has grown to over 800 subscribers, primarily patients, caregivers, and physicians. The format is reminiscent of the earliest newspapers in which readers themselves contributed most of the material as "correspondents" in the literal sense of the term.

The ALS Digest appears approximately weekly. It functions as a heavily moderated computer conference or bulletin board. Participants send email messages to the editor, who makes a selection for publication and adds other material of his own choice. The emphasis is very much on the distribution and exchange of information, however, personal matters are sometimes discussed as well. Typical issues contain exchanges on such things as experience with voice synthesizers and where to get them, reports by participants in drug trials, questions and answers about medical problems and symptoms, abstracts of relevant medical articles, lists of online information resources, addresses of drug companies, news of patients' condition or death, and so on. Often patients or caregivers pose difficult questions concerning management of symptoms in the hope that someone among the subscribers will have had previous experience to share. Generally their hope is not disappointed. This information exchange function is one of the most successful applications of CMC.

The emphasis on information of course raises issues concerning rumors and accuracy. The editor is not a physician and claims no special expertise. Thus the level of rationality of the exchanges must be set by the participants themselves. This is a risk in all self-help groups. It is interesting to see how it is handled online.

There is no problem with the exchange of advice on devices and symptoms, but one wonders about the efforts of patients to cure themselves. Where these efforts are channeled by clinical trials, many of the patients seem remarkably objective, reporting lack of progress with treatments now considered ineffective. More worrisome are questions about faddish treatments and self-treatments, particularly in the light of the rapid spread of rumors about neurontin that has so preoccupied patients this past year.

In fact the group does appear to have the resources to protect itself from the worst kinds of mistakes. For example, one patient asked about the safety of megadoses of B complex vitamins. The reply warned him off, and of course others reading the exchange as well. Incidentally, the reply came from England. In another case, someone who describes himself as "working in a lab", responds negatively to a question about the beneficial effects of ozone therapy.

One whole issue of the journal was devoted to answering questions about the supposed dangers of mercury amalgam. The issue begins with a disclaimer from the

editor who reminds his readers that the ALS Digest is not a scientific journal. The respondent is not identified as to profession, but does appear to have a scientific background. He expresses an unfortunate willingness to consider mercury as a culprit but offers plenty of authoritative evidence that exposure from fillings is trivial compared to permitted levels in occupational settings. Scientific references are included for those interested in following up on the issue.

On the whole, the scientific level of the publication is fairly high for a lay journal. Occasional comments by physicians indicate that some serious watching is going on, however it is clearly impossible for professionals to police the networks for misinformation. Since this type of communication is not going to go away, we must design effective intervention strategies to contribute appropriate cautions in an economical and authoritative manner.

Prodigy Medical Support Bulletin Board

The ALS discussion group on the Prodigy Medical Support Bulletin Board is a very different operation. This is an unmoderated conversation between dozens of patients and caregivers with the emphasis on social support. There are about 500 reading the exchanges.

Much of what goes on resembles the exchange of news about clinical trials, symptomatic treatment and devices typical of the ALS Digest, but there is less scientific information. However, the unedited conversation contains much more frequent and open personal self-expression. The tone is warm and friendly. Interestingly, the politics of ALS come in for considerable discussion as well.

Much of the social support consists in exchanges of encouragement and feelings. As an example of a more delicate social support function the bulletin board was able to fulfill, there was a long running discussion of problems of sexuality. Patients and caregivers wrote in both general and personal terms about the persistence of desire and the obstacles to satisfaction.

The frankness of this discussion may owe something to the fact that it was carried on in writing between people whose only connection was the computer. It is well established that computer messaging diminishes the sense of vulnerability that often inhibits discussion and behavior in face to face settings. Thus here is a case where the very limitations of CMC offers something positive.

It is also interesting to note that Prodigy discussion participants actually organized themselves to try to influence ALSA. A list of priorities was discussed and eventually presented in a meeting to the association. The "demands" included combination trials and the replacement of placebo by historical controls. These interventions in the design of clinical research by subjects and potential subjects resemble activities in the AIDS community. However, ALS patients appear to have adopted much less confrontational strategies. I will have more to say about this development later.

Social Support

I would like to turn now to an evaluation of the larger implications of these online networks.

There is enough evidence of the efficacy of social support that its value to patients is no longer in question. Research shows that the number and quality of social ties correlates with individuals' ability to manage stress and to cope with difficult life situations. Patients with the most social support suffer less depression and adjust more successfully to their condition. There are even studies which show longer survival in cancer patients with more social support. Social support is no doubt particularly important to ALS patients who suffer a chronic illness that can be quite isolating and depressing.

However, it is much less clear how to enhance patients' social support in the framework of existing medical institutions. Hesitation about medically initiated social support has gone along with rapidly expanding interest on the part of patients in selfhelp groups. The online patient meeting must be seen in this context.

Selfhelp groups generally fulfill two missions which we have seen exemplified in the online environment. On the one hand, selfhelp involves learning to understand and cope with illness. Selfhelp groups often invite the participation of professionals in educational roles, and organize the exchange of information among patients about treatment and strategies for daily living. On the other hand, these groups pay much more attention than do physicians to personal feelings such as stress, depression, loss of self-esteem, guilt, and so on. The research seems to show that professionals are most helpful in providing information to selfhelp groups while other functions are best served by the patients themselves.

In these respects, online patient meetings are surprisingly similar to conventional selfhelp groups. Professionals play a limited educational role while information exchange and emotional support are handled by the patients. The switch to virtual interaction seems to change far less than one might have expected.

Changing Patient Roles

There is, however, another way to look at the online patient meeting that suggests deeper differences. Selfhelp groups, after all, are small and localized. With the exception of AIDS patients they have wielded little political power. If AIDS patients have been the exception, that is because they were "networked" politically by the gay rights movement even before they were caught up in the network of contagion. Will online networks have a similar impact on other patient groups? This question concerns the evolution of the sick role in our society.

Contrary to popular belief, this term refers not to a bad adjustment to illness but to the normal social expectations of the sick. Talcott Parsons defined the sick role as a condition of legitimate withdrawal from social responsibility in exchange for a commitment to trying to recover. Parsons saw sick role behavior as a tolerated form of deviance. The great problem the sick role was designed to solve was the risk that the sick would organize themselves as an interest, and therefore they were systematically isolated from each other.

It is clear that the demands of the sick role and social support clash. Perhaps this is not a serious problem for the majority of acutely ill patients whose condition is reflected in the role. But chronically ill patients are sometimes harmed by conforming too fully to their normal role. The widespread emergence of selfhelp groups testifies to the poor fit of the role and their needs. To the extent that medical research and institutions have

sanctioned these new forms of organization of patients, they too are involved in transforming the sick role to better adapt it to the needs of the chronically ill.

With the emergence of online patient meetings, this process appears to be entering a new phase. The example of the effective mobilization of patients to bring forward demands on ALSA points to the powerful organizing potential of computer networking. Groups with hundreds, even thousands, of members can form rapidly, inexpensively, and on a long-term basis. Although primarily devoted to traditional selfhelp tasks, they can quickly poll their members and present views that have credibility as representative. We may well be witnessing the beginning of a new kind of empowerment of patients which will require more responsive medical institutions as a consequence.

This prediction has two significant trends in its favor. On the one hand, we have seen a rising demand by various groups of patients for more control over their own relation to medical care. Noteworthy examples include the push for Lamaze childbirth education in the 1970s and the more recent struggles of AIDS patients for access to experimental treatment. On the other hand, students of information technology have been arguing for a decade that new forms of communication will require more participatory organization in business, education, and other fields. With the emergence of the online patient meeting, these trends have intersected. It will be interesting to watch further developments in this domain.

For Further Reading

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