FROM CHURCH BASEMENTS TO WORLD WIDE WEB SITES: THE GROWTH OF SELF-HELP SUPPORT GROUPS ONLINE

EDWARD J. MADARA, M.S.
Saint Clare's Health Services, Denville, New Jersey

ABSTRACT

Online computer technology is dramatically increasing the number, utilization, accessibility, and capabilities of mutual aid self-help groups. It has done this, in part, by enabling many people to overcome barriers that previously kept them from organizing or participating in traditional face-to-face groups. The Internet and other online services provide individuals with new worldwide opportunities for developing and participating in different electronic mutual help communities. While they have their own special characteristics and capabilities, the online self-help groups provide many of the same benefits as the traditional face-to-face groups.

One patient with terminal cancer, until the day before he dies, used a laptop computer to reach out to others from his hospice bed, sharing his thoughts and feelings, and teaching others the visualization techniques he had found helpful in dealing with his own illness. Worried parents of children with hydrocephalus, while they have been told by physicians that their children would do fine, find special comfort in their online listserv conversations with adults with hydrocephalus who have graduated college, married, and have children of their own. A woman from Michigan with a rare connective tissue disease communicated for the first time with patients in Florida and California, and a national Foundation for Ehlers-Danlos syndrome is later founded. A recovering alcoholic in Mississippi, struggling to stay sober, goes online and reports "suddenly a beautiful message of strength and hope shows up on my computer screen from an AA member in Japan" (M., 1993).

As the availability and popularity of online and Internet services continues to grow and change the worlds of healthcare, business, communications,

entertainment, and government services, many more individuals and existing self-help groups are using the medium to share their experiences, strengths, and hopes online. The majority of the largest one hundred self-help groups now have Web sites or e-mail addresses. But the traditional face-to-face national groups are, for the most part, relative latecomers to the online world. Beginning in the very early 1980s, it was the pioneering efforts of individuals, often members of established groups, who acted on their own to develop the first mutual help message boards and BBSes (Bulletin Board Systems).

As the cost of computers declines and their availability increases, more people are using online access to share common concerns, practical information, and emotional support with others. Whereas the average American has had several dozen different face-to-face self-help groups that he or she might attend in their local area, that same person with a computer, modem, and online access, now has a minimum of over one thousand group "meetings" in which they can participate from their home, office, or increasingly from their public library or community center.

The new computer networks that provide mutual help through message exchanges or actual group meetings, are a unique entity with distinct advantages and disadvantages for building and providing community. Online mutual help groups, like their community face-to-face counterparts, are helping people with a wide range of illnesses, disabilities, or other stressful life problems or transitions. They, too, reach out and support family members and friends who are often the "hidden patients" under stress. While they lack some of the helpful opportunities found in face-to-face groups (non-verbal communication, handshakes, hugs, and human presence), they do provide support, information, and a sense of belonging. For example, the online meetings are "not cold or impersonal as one would think a computer would be," i.e., people find friends, exchange home phone numbers, and worry if someone hasn't been heard from or "seen at a meeting" (Miller, 1991).

But most importantly, computer telecommunication is enabling many more people to overcome some of the traditional barriers to face-to-face self-help group participation: the lack of an existing local group to attend in more rural areas, the twenty-four-hour a day caregiver responsibility by the bedside, the lack of transportation or time available for travel, rarity of the illness or condition, and the limitations of even the most severe physical disabilities or hospital-bound patient. The online support networks provide distinct advantages that have also prompted the development of new groups not seen in the community, e.g., support groups for shy persons, or those with severe agoraphobia.

It's important to recognize that people have always used the most appropriate technology for mutual help, whether it be the letter-writing "committees of correspondence," the telephone networks for a group buddy system, or the church mimeograph machine for an interactive newsletter. So, too, online mutual will always piggyback on the expanding and practical technology, having started

with local home-based BBSes and forums on CompuServe, it has moved on to the Web sites accessible through local Internet providers or Web TV. As the technology continues to change rapidly, we can expect people and groups to utilize the most practical and economical forms of online technology and services. As the phone, cable, entertainment, and Internet technologies merge, and the battles over bandwidth and service access providers are won and lost, new forms of integrated computer, telephone, VCR, video game player, Internet, and television technology will evolve to meet the needs for support mutual help networks.

THE COMMERCIAL INFORMATION SERVICES

A person's first experience with self-help online, up until recently, usually has been with one of the larger commercial computer networks, like America-On-Line, Prodigy, or CompuServe. They all offer users the ability to read, post, and exchange messages on message boards within various forums; search various database libraries; conference and "chat" with others in one-to-one or "online" group meetings; send and receive e-mail from anywhere on the Internet; and access Internet sites. The commercial services provide their own software, which is relatively user-friendly. They charge various fees for set number of hours monthly or for unlimited online use of their service and the Internet.

CompuServe, one of the oldest services, has increasing international participation. Most of the mutual help takes place within the variety of forums that provide people with the opportunity to meet others who have experience with their issue. Similar to other systems, the forums have three primary capabilities: message board, database libraries, and live conferencing. The message boards are broken down into some twenty specialty sections or categories, wherein individuals can post messages with the subject of their choosing. Examples of groups include a variety of those 12-Step groups that schedule meetings in the Recovery Forum, to an Early Hysterectomy Support Group in the Women's Wire Forum, and from Migraine Sufferers in the Health & Fitness Forum to AIDS patients meeting in the Human Sexuality Forum. For a listing of forums, the "index" search engine is usually used.

America-On-Line is primarily a national system, but is expanding internationally. AOL has an extensive number of real-time self-help group meetings. Major AOL forums related to health include: Better Health and Medical Forum, disAbilities Forum, Issues in Mental Health Forum, Fitness Forum, and Gay & Lesbian Community Forum. Each forum has its own extensive text databases, message board, and software library. A special forum of note is SeniorNet, geared to persons fifty-five and over, which was originally started at the University of San Francisco as a computer training program for seniors.

AOL also has smaller forums or sections for four national self-help organizations: the National Alliance for the Mentally Ill (for families of the mentally ill),

the Multiple Sclerosis Society, the National Cerebral Palsy Association, and the Older Women's League.

Comprehensive listings of self-help group meetings on AOL were compiled and posted in different forums for over a year by a volunteer who used the pseudonym "Dan Ash." However, his subsequent attempts to develop a central index or area specifically for self-help groups were thwarted, as one forum administrator accused him of being a third party information service provider in violation of AOL policy.

Prodigy, a national service, has had one of the early and most economical forums for mutual aid, called the Medical Support BB which has dozens of different health-related message boards. Other forums providing health-related information and discussions include the Health Board and the Crohn's and Colitis Forum, which is by the Crohn's & Colitis Foundation of America.

Other national networks include MicrosoftNet, and Delphi which carries WID-Net, an international service run by the World Institute on Disability for persons with disabilities.

THE BBSes

The earliest and most economical of the online services were the hundreds of Bulletin Board Systems or BBSes across the country, that could be called for free almost twenty-four hours a day. These were often run out of individual's homes by simply calling a phone number. However, with the increased availability of Internet access at lower rates, the use and number of BBSes has declined greatly.

THE INTERNET

Self-help support networks on the Internet take three primary forms. The first are the "mailing lists" or listservs that allow members to receive messages delivered to their e-mail address and send out messages and responses that can go to all who are on the subscription list. Some examples are "BRAINTMR" for persons who have or have had brain tumors sharing their personal experiences, or "TRNSPLNT" for organ transplant recipients and anyone else interested in the issues, experiences, and realities of living with an organ transplant. Another example is the SLFHLP-L research mailing list that is for any faculty, students, or self-help group leaders interested in discussing research of self-help group issues.

A second way that people share their experiences and solutions is through the newsgroups on the "USENET" network on the Internet. Usenet provides access to thousands of "newsgroups." A newsgroup stores messages on a computer in a central location, which can be read and replied to by users.

The third major form of mutual help found on the Internet is the growing number of Web sites that provide interactive message boards or real time chat

meetings. There are an increasing variety of different Web site software programs that permit live real-time "chat" programs (like the original IRC or Internet Relay Chat) and interactive message boards. Within Web sites, individuals can simply click or "hotlink" upon a name or figure to be automatically taken to another section at that Web site or to a different Web site on the Internet. Many national self-help groups, like the National Alliance of the Mentally Ill (http://www.nami.org) also provide Web page sections that offer news on upcoming publications, conferences, pending legislation, and current research, as well as providing online membership registration.

Many individuals continue to develop personal Web sites whereby they seek to share their experiences with others and gain others' insights, from a parent of a child with leukemia (http://www.squirreltales.com/), to a young adult dealing with severe head injury following a bike crash (http://users.aol.com/ggooseiiii/bikecrash.html). The sharing of personal stories runs from those based on books, e.g., the Car Accident Trauma Recovery Circle (http://www.stresspress.com/car), to those of fledgling self-help groups such as "Second Wind" National Lung Transplant Association (http://www.web-site.com/2ndwind.htm) for candidates for, and recipients of, lung transplants.

The most comprehensive listing of hundreds of self-help Web sites, listservs, and newsgroup resources is maintained by John Grohol, who developed Mental Health Net, a comprehensive Web site database of mental resources, articles, and discussion boards at the Web site address http://www.cmhc.com/selfhelp.htm

In 1996, in partnership with Dr. John Grohol and his CMHC Systems, Inc., the American Self-Help Group Clearinghouse national and international group database was placed online within Mental Health Net. Here, individuals can tap a search engine to learn about any of over 800 national and international self-help support groups, as well as individuals seeking to start any needed new support networks, for different illnesses, disabilities, addictions, bereavement situations, and other stressful life problems. Hotlinks to Web sites and/or e-mail addresses for hundreds of groups are included in the Clearinghouse descriptions. Also listed are self-help group clearinghouses worldwide, self-help group resources, general how-to's on starting a group, samples of research, and a registry for those interested in starting new support networks that do not yet exist in any form. The URL for the American Self-Help Clearinghouse is http://www.cmhc.com/selfhelp/

STAND ALONE SOFTWARE AND RELATED ONLINE PROGRAMS

Provisions for the development of peer support networks are being integrated into computer-assisted self-care programs. Under the byline "Armed with Modems and New Software, Patients Are Quietly Reinventing Health Care," Newsweek (Sept. 26, 1994) described how programs that provide self-care edu-

cation and put patients in touch with one another via computer, were improving patients' lives and reducing their medical costs, e.g., the University of Wisconsin CHESS software program (used as a take-home rehab program) had reduced the medical bills of AIDS patients by 30 percent and resulted in shorter hospital stays. The CHESS private telecommunications program has also brought women with breast cancer together to help one another.

Cleveland State University's TALknet system allows patients to start discussion groups via touch-tone telephones, without the need for a computer. The unseen computer can be placed at a hospital clinic to simply operate a user-friendly voice bulletin board with an audio, rather than video, menu. An initial study of pregnant women who abused drugs and used the system found that 55 percent of the voice messages left on the board were for "emotional support of each other." Moreover, those using the voice bulletin board reported significantly lower rates of clinic visits with no decline in health status (Alemi et al., 1996).

CHARACTERISTICS OF ONLINE SELF-HELP NETWORKS

Based upon personal observations over sixteen years, there are several online characteristic aspects to note. First, while more online self-help group meetings are being held in real time, the most prevalent forms of mutual help are the message threads to be found in message boards on every system. The discussion threads almost take on the form of a self-help group in slow motion. Unlike real-time mutual help, responses are usually carefully and thoughtfully prepared offline before being posted in response. This asynchronous communication is often richer than the real-time meeting exchanges. As one pioneering researcher (King, 1994) of online addict recovery groups has noted:

> There are advantages and disadvantages to the sharing of recovery tools and experiences via ESGs (Electronic Support Groups). Among the advantages are the thoughtfulness of the replies to issues that recovering addicts face in common. Writing can be different from spoken conversation in that thoughts can be formed more slowly and edited more carefully. The experiences and personal triumphs, as they are expressed in written form, may seem more powerful and clearer than similar messages shared in person at a meeting of AA or NA (pp. 48-49).

The medium is available twenty-four hours a day. It is not as intrusive as a phone call, since one enters the system to receive messages only when desired, and is immediately advised of any waiting messages.

Online self-help networks also appear less structured than traditional self-help groups. This is due to the dependence of many on the impromptu flow of messages, and often the lack of clear leadership. An exception is the 12-step groups,

which appear to be faithfully following program formats for their meetings. Most of the online self-help networks are being developed by individuals who have the problem. Some existing national self-help organizations are just beginning to move online, often after some members may have established a presence of their own.

Currently, online communication is an equalizer. In communicating with other people online, there are no visual distractions. There are no signs of social status, age, dress, weight, race, or appearance. People are seen for their words, ideas, and emotions when they decide to express them. A substitute to aid in expressing emotions are a range of punctuations called emoticons to express, e.g., a smile :-), surprise :-o, or hugs for a person (((recipient's name))).

On the majority of networks, users can have anonymity. Their name may not appear in their system address or they may use a handle. This, combined with the lack of visual feedback, appears to help many people, who may not feel comfortable speaking at a face-to-face group, to express their feelings more readily, as reflected by the fact that all the major online services have shyness support group sections wherein shy people help one another.

This same anonymity may permit a few people to engage in serious verbal abuse or profanity toward another, with whom they may disagree. Referred to as "flaming," the behavior is prohibited on the major forums and action can be taken there, and on BBSes, to remove the violator.

Online self-help is being used by many more people who would otherwise be unable to attend a self-help group. This includes those in rural areas, caregivers, and those with serious disabilities. In the online world, major disabilities disappear. As Georgia Griffith, who happens to be deaf and blind, and ran weekly CompuServe meetings on disability for over eight years, expressed it, "it's the executives who cannot type who have the true disability in this new world."

As the number of persons online grows, it becomes easier for those who share a less common or a temporary health concern to meet. New types of support networks are developing online that do not exist in the community. For example, the number of people who have recently had or are anticipating gall bladder surgery has led to the development of a "Gall Bladder Club" discussion section on Prodigy. Mothers with physical disabilities meet on America-On-Line to discuss issues such as how to best transport their child in their wheelchair with them. While no support groups exist in the community for veterans with Persian Gulf Syndrome, there are Friday night meetings of veterans and their families from the United States and Canada on America-On-Line.

A last noteworthy characteristic of online groups is that they are open to a worldwide membership. The globalization of online self-help is reflected by the variety of members who participate from different countries. So too, the Internet has made it easier for supporters of self-help groups to exchange perspectives worldwide. A recent example of the latter are the e-mail interviews conducted by Tomofumi Oka that contrasted support for self-help groups in the United

States, Germany, and Hong Kong. These interviews are easily available on the Internet (http://pweb.sophia.ac.jp/~t~oka/res/selfhelp/papers/Normal).

WHAT THE ONLINE NETWORKS PROVIDE

Like their face-to-face counterparts, the online groups and networks meet basic human needs for understanding, support, education, and advocacy.

Social Support

Patients and their family members find relief from isolation. They share their experience with others who have "been there." Many enjoy a sense of belonging or "community." Similar to any face-to-face self-help group, through these electronic exchanges people are finding help and understanding from those who have "been there." A man who accidentally stumbles into an online AA meeting and initially argues that his drinking habit is not that of an alcoholic, leaves with a commitment to get help. A single mother who lives in a very rural area, shares her experiences with other single parents. Teenagers who have physical disabilities or chronic illnesses share their feelings on a Toronto BBS (Lefebvre & McClure, 1995). An elderly widow wakes at 2 A.M. and logs on to SeniorNet to participate in discussions that range from coping with health problems to current events.

Practical Information

Practical information is available for coping with the twenty-four-hour a day problems associated with a chronic illness, disability, or other stressful life problems, as well as on outside community resources (entitlements, housing, healthcare, legal info, employment). Such information is provided in response to message requests and is uploaded to libraries by members.

Shared Experiences

Members share their experiences, strengths, and hopes. The spectrum of members' experiences and coping skills often provide them with a range of options or alternatives for problem solving. It also helps with normalization and feedback.

Positive Role Models

People have the opportunity to meet veterans of the illness, who model competence and attest to how problems can be overcome. Such associations are rarely possible in the professional milieu. These relationships encourage and inspire group members to responsible action and further learning.

Helper Therapy

A key feature of traditional self-help groups has been the ability of individual members to help others within the group, thereby increasing their sense of self-esteem and self-worth and helping themselves. Self-help networks, or mutual help networks as they may be more appropriately described, are therefore especially suited to these new telecommunities, where it is the common culture and ability of any user to become a resource provider and offer information and support to others. One observation from a physician who has studied online self-help groups is that "In the online world, the wisest and most generous self-helper is often the one with the gravest problem or the worst prognosis" (Ferguson, 1996, p. 41).

Empowerment

People see how others have taken responsibility for their health and recovery, and thereby are encouraged to be more health-active. The mutual helping process increases their sense of self-esteem at a time they often need it the most, whether it be a widow or a drug addict. They take what is perceived as a deficit (the illness, addiction, or loss) and recognize it to be the asset it is for them to provide understanding, help, and support to others.

Tom Ferguson, M.D., (1996) has pointed out that

> By encouraging layfolk to be overly-dependent on doctors, we have inadvertently disempowered the populace in health matters. And in so doing, we have turned potentially powerful, knowledgeable, health-responsible citizens into ignorant, fearful, isolated clients of professionalized health care. The rise of consumer health informatics and online self-help provides the perfect opportunity to remedy this situation (1996, p. xvi).

Professional Support

Some online groups or forums attract professionals who serve to answer general questions, or serve as ad hoc or formal advisors, while other professionals speak at online meetings to share their professional knowledge and learn more about the experience of illness and other stressful life problems.

Advocacy Efforts

When there are larger issues that a lone group cannot resolve online, they may become involved in national or international advocacy efforts, e.g., online networking by persons with disabilities played a part in the passage of the Americans with Disabilities Act. Some online groups envision increased advocacy potential of telecommunications. "There aren't diabetes recovery groups as such," says Dave Groves, who runs the Diabetes Forum on CompuServe. A diabetic himself, Groves feels his forum provides practical and frank discussions,

especially for those who are newly diagnosed. His experience has been that hospital-run groups are all too often fairly stern lectures that provide far too little attention to discussions of what it means to be a diabetic. But Groves notes that "if I could ever unite the 12 million diabetics in the U.S., we'd have a voting bloc that could really get things done."

Accessibility

The traditional face-to-face self-help groups are known for their easy accessibility: financially accessible because they do not charge fees; geographically accessible because of their community location and meeting times; and greater psychologically accessible because of the acceptance and understanding they provide and, in many cases, the anonymity they can give. The online groups increase accessibility even further. As cited earlier, the online systems are overcoming barriers of distance, time, and disability. But barriers to universal access need to be overcome. Populations, such as the poor, those with severe disabilities, the chronically ill, and their caregivers, stand much to gain from such access, which would provide healthcare information and mutual aid support. Lack of universal access to telecommunications systems, resources, and networks, represents a significant barrier to maximizing the personal self-care and well-being of all Americans.

LIMITED ONLINE RESEARCH

Research of online self-help groups is only in its infancy. The easy and direct access, that students and researchers have to many online self-help groups, combined with group members' concerns for privacy, has already created some initial problems resulting in a number of online groups prohibiting uninvited research. But some cooperative research has been conducted. In one case, one of the researchers and her husband were already members of an online cancer support group on CompuServe. That study found that the vast majority of respondents rated the online support group as most helpful, especially for the group's ability to help them lessen their "sense of isolation," obtain needed information, "put cancer in perspective," and even permit them "to help others" (Fernsler & Manchester, 1997).

In a second study of 1,863 messages of 533 participants in an online newsgroup for persons suffering with depression, high levels of support, acceptance and positive feelings were found. Forty-nine percent of the messages posted conveyed some type of social support specifically intended to help another member. Positive comments were observed seven times more frequently than negative ones (Salem et al., 1997). A third survey (Ferguson, 1999) requested one thousand members of illness support groups operating at one Internet Web site for their perceptions of the helpfulness of their online group

compared with their general physician and specialist in meeting twelve areas of patients' needs. While the author admits that the low response rate (19%) may have biased the sample, his returns did find that the online groups ranked significantly higher than either generalists or specialists in areas of convenience, cost-effectiveness, emotional support, compassion/empathy, help in dealing with death and dying, medical referrals, practical coping tips, in-depth information, and "most likely to be there for me in the long run."

SUMMARY

Online support networks, especially for the less common or newer illnesses, will continue to evolve as Web sites serve as "lightning rods" for individuals with those problems. Such networking has often been one of the first activities that leads to the early identification of new or growing health or social problems, the organization of actual mutual aid self-help groups, and the development of more formal health and social service organizations.

In collaboration with professionals, online groups can also provide beneficial feedback for improving services and systems. As former Surgeon General Koop concluded:

> Health and human service providers are learning that they can indeed provide a superior service when they help their patients and clients find appropriate peer support . . . The future of health care in these troubled times requires cooperation between organized medicine and self-help groups to achieve the best care for the lowest cost (from foreword in Katz et al., 1992, p. xviii).

At the end of this second millennium, online computer telecommunication shows itself to be the most powerful and promising tool for expanding mutual aid self-help. While helping to retain many of the basic dynamics and benefits of traditional self-help groups, it is already dramatically increasing the number, utilization, accessibility, and capabilities of self-help support groups. With the increased availability of online computer networks throughout the world, these new forms of electronic community will continue to multiply and help more people meet their needs for support, knowledge, and empowerment.

REFERENCES

Alemi, F., Mosavel, M., Stephens, R., Ghadiri, A., Krishnaswamy, J., & Thakkar, H. (1996). Electronic self-help and support groups. *Medical Care, 34* (Suppl. 10), OS32-OS44.

Ferguson, T. (1996). *Health online: How to find health information, support groups, and self-help communities in cyberspace*. NY: Addison-Wesley.

Ferguson, T. (1999). Original research: E-patients prefer e-groups to doctors for ten of twelve aspects of health care. *The Ferguson Report: The Newsletter of Consumer Health Informatics and Online Health, (1).*

Fernsler, J. I. & Manchester, L. J. (1997). Evaluation of a computer-based cancer support network. *Cancer Practice, 5* (1), 46-51.

Lefebvre, A. & McClure, M. (1995). Ability online, children in hospital now in touch with world. *Leadership, 4* (6).

Katz, A. H., Hedrick, H. L., Isenberg, D. H., Thompson, L., Goodrich, T., & Kutscher, A. H. (Eds.) (1992). *Self-help: Concepts and applications*. Philadelphia: Charles Press.

King, S. (1994). Analysis of electronic support groups for recovering addicts, *Interpersonal computing and technology* (Washington, D.C.: Center for Teaching and Technology, Academic Computer Center, Georgetown University)*, 2* (3), 47-56.

M., N. (1993). An electronic awakening. *AA Grapevine*, 2-4.

Miller, H. G. (1991). How do you feel?: A CompuServer's guide to taking charge of your health & fitness. *CompuServe Magazine*, 12-18.

Salem, D. A., Bogat, G. A., & Reid, C. (1997). Mutual help goes on-line. *Journal of Community Psychology, 25* (2), 189-207.