"A VIRTUAL HUG": PROSPECTS FOR SELF-HELP ONLINE*

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ABSTRACT

With the rapid growth of information technologies, self-help initiatives have drawn on the power of the Internet to connect individuals in ways not possible using traditional formats. This article examines the challenges and prospects for online (Internet) self-help and mutual support. First, a model (Functions of Self-Help) is introduced comprised of three key components: 1) information sharing and experiential learning; 2) social support; and 3) empowerment and advocacy. The model is then used to evaluate the pros and cons of Internet applications of self-help, through an examination of published studies of self-help groups along with interviews with key inform- ants. Major findings indicate that online groups offer new and approachable avenues for realizing the Functions of Self-Help. Limitations do exist, however, in relation to access and concerns about emotional support within a virtual environment. A research agenda is described for addressing key questions about online self-help, including prospects for integrating online and traditional approaches.

> I'd like it to be able to give me a hug.
> *A teen's suggestion for improving the Internet*

Although self-help/mutual support began with face-to-face groups, the advent of information technology has given birth to a dramatic growth of groups online (Madara, 1999). Information and communication technologies (ICT) open up new opportunities for eHealth and consumer engagement through sharing information, ideas, and experiences (Skinner, 2002; Norman, Chirrey, & Skinner, 2002). However, there are many unanswered questions about self-help groups that operate online compared with traditional face-to-face approaches. How are the experiences of traditional self-help initiatives played out in the online environment?

The Internet has experienced an explosive growth rate—by September 2003 there were over 680 million users worldwide (Global Reach, 2003). Increasingly, the Internet is being used as a key source of information and support (Eysenback, Sa, & Diepgen, 1999; Riegelman & Persily, 2001). For example, Lombardo et al. (2002) describe how youth activists use technology to build sustainable networks for social change. New technologies provide expanded ways for youth to share information and experiences, which is a key success factor for social action initiatives. Similarly, self-help initiatives have drawn on the power and potential of the Internet to connect individuals with common conditions and concerns. Although precise estimates are not available, many self-help groups have migrated to online formats and new ones have emerged. There are hundreds of online self-help groups for addictions, bereavement, mental health, abuse, parenting, caregiver concerns, and other stressful life situations.

However, the rapid growth in Internet use can stimulate overly optimistic expectations regarding consumer applications of eHealth. Skinner et al. (2003) point to a host of issues affecting the quality of access, such as: timeliness, literacy, privacy, relevance, gate-keeping, and system functionality (bandwidth). These pose barriers for disadvantaged populations that could benefit from online self-help groups (Robert Wood Johnson Foundation, 2001). Moreover, research on self-help support groups presents a number of challenges (Dadich, 2003) and ethical dilemmas for online environments (Flicker, Haans, & Skinner, 2004).

This article examines the challenges and prospects for online (Internet) self-help groups. A model is introduced describing three key Functions of Self-Help: 1) information sharing and experiential learning; 2) social support; and 3) empowerment and advocacy (see Figure 1). This model provides a basis for evaluating the pros and cons of Internet applications of self-help groups. Attention is given to the integration of traditional and online formats, to maximize their differential benefits. Finally, some key research needs are described and an agenda for action is proposed.

UNDERSTANDING SELF-HELP

Self-help groups are formed by people with a common experience, who come together to share personal stories, empathy, and support. Through self-help, people coping with chronic illness, disability, or other stressful life problems
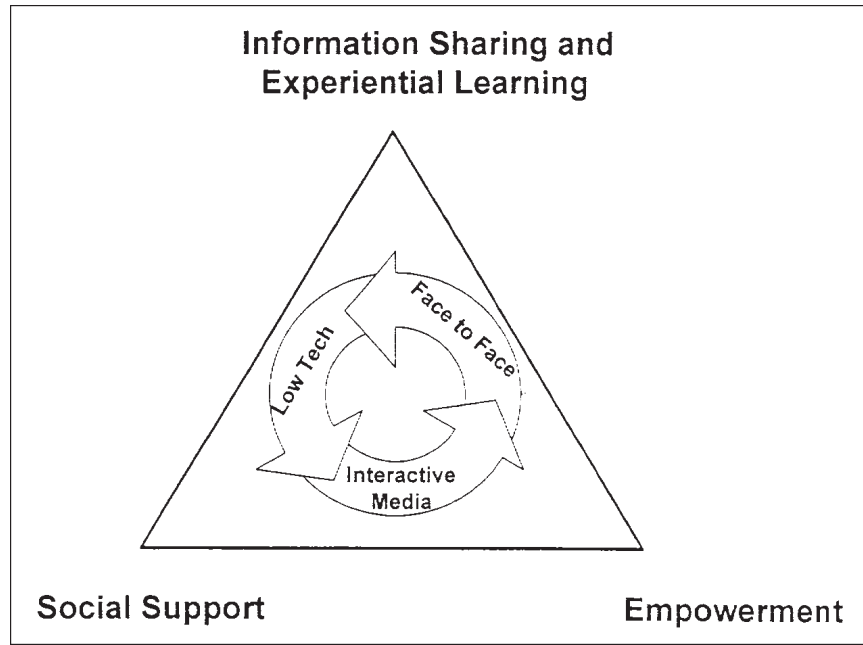
Figure 1. Functions of self-help and technology options.

find relief from isolation and begin to normalize their experiences (Madara, 2000). Although the term "self-help" predominates, many experts in the field also use the terms "mutual aid" or mutual support" to invoke the peer-based nature and supportive aspects inherent to the ideology (Madara, Kalafat, & Miller, 1988).

In addition to mutuality and support, a fundamental tenet of self-help groups is that they are owned and run by group members themselves. Although professionals may take part in the self-help process at the request and sanction of the group, their involvement is typically limited to external, consultative roles (Hyndeman, 1996). This distinguishes self-help groups from other support-type groups that are formed and led by health professionals, though the two approaches do share many common elements. Borkman (1999) discusses the relationship between self-help and other support-type groups in relation to authority and ownership. The two types are furthest apart when professional authority and ownership are concentrated, and overpower the experiential knowledge of the group participants. However, when professionally led support groups foster and deepen the worth of participants' experiences, they can be understood to be incorporating a self-help approach.

Despite operating on the periphery of the formalized health care system, a growing recognition of the value of self-help is emerging in health care and

health promotion. According to Madara et al. (1988), many professionals have recommended the inclusion of self-help groups in comprehensive care systems. Self-help provides social support and connection, which has been shown to improve chances of favorable health outcomes (House, Landis, & Umberson, 1988; Thoits, 1986). Social support functions as a buffer against the emotional and physical impacts of stressful life events and internally induced stressors (Hyndeman, 1996). In addition, there is evidence that individuals involved in self-help groups take greater control and responsibility over their own health and well being (Hyndeman, 1996; Stewart, 1990). Moreover, self-help groups honor the World Health Organization's health promotion goals to create supportive environments, develop personal skills, reorient heath services, and strengthen community action (WHO, 1986).

FSH Model

In an effort to conceptualize the self-help group process, we propose a model that describes the Functions of Self-Help groups:

- information sharing and experiential learning;
- social support; and
- empowerment and advocacy.

In Figure 1, these Functions are shown in a triangular relationship. Information sharing and experiential learning are at the apex of the triangle, depicting a process in which social support, empowerment, and advocacy arise through group exchange and connection. By sharing their experiences, individuals gain practical information for coping, as well as a sense of belonging and community. The resulting social support helps to reduce isolation and normalize experiences. Individuals are empowered by serving as sources of help and support to others, and may engage in collective action and advocacy related to their common experience. Different levels of technological connection enable this group process, from face-to-face meetings to low-end technologies such as the telephone, to higher-end, more interactive technologies such as e-mail and the Internet.

ONLINE PROSPECTS

Table 1 summarizes the pros and cons of online self-help, drawing on the Functions of Self-Help model. Data for our analysis comes from published reports of self-help groups, as well as interviews with five experts in the field.

Information Sharing and Experiential Learning

A primary focus of self-help groups is the sharing of information around the group's common issue or concern. Such information may consist of technical

Table 1. Pros and Cons of Online Self-Help

	Advantages	Limitations
Information sharing and experiential learning	• Large volume and variety of information • Written permanent record • Access for those who cannot meet face-to-face	• Requires computer technology and literacy • Concerns about the quality of health information online • English dominated (at present)
Social support	• Support available 24 hours a day • Online environment "erases" existing hierarchies • Anonymity may overcome self-disclosure barriers	• Not possible to receive physical reinforcement online • Individual confidentiality is questionable • Possible limited potential for emotional support
Empowerment and Advocacy	• Sense of control in coping with difficult situations • Helper therapy—being helped by helping others • Strength in numbers	• Advocacy may deflect group from original self-help focus • Danger of professional cooptation • Difficult to measure and define

materials, such as research findings. However, the most common and important form of information shared within self-help groups is experiential knowledge. This is defined as "information and wisdom gained from lived experience," and is a central tenet of self-help ideology (Schubert & Borkman, 1994). Experiential knowledge most often consists of personal reflections in which members share their experiences, strengths, and hopes. By relating their stories and struggles, individuals share practical information about what has worked for them, develop positive role models, and get support and feedback (Madara, 2000).

The online environment has many characteristics that make it a promising venue for connection and experiential learning. The ability to connect to groups and individuals without time, transportation, or geographic concerns opens up access to those who have been traditionally marginalized from self-help groups, such as individuals who are shut-in or those living in rural communities with few services (White & Dorman, 2001). Online self-help has been shown to be an effective form of support for caregivers, for example, as they are often confined to their homes as a result of their responsibilities (Milio, 1996). The diversity of people and information available online allows individuals to share experiential knowledge across great distances, and to form relationships that are often not

possible face-to-face. People with rare medical conditions, for example, have the opportunity to connect with the few others who share their experience (White & Dorman, 2001).

Online groups can also provide access to people with physical disabilities, by overcoming constraints related to mobility issues and allowing for the integration of technologies such as special keyboards and Braille printers. Technology can also help disabled and non-disabled individuals connect around a common issue such as alcohol addiction, whereas many face-to-face groups are often unable to accommodate particular disabilities.

The online environment encourages focused knowledge sharing and assistance, due to the written nature of communication and the record it creates. Detailed step-by-step approaches to problems can be delineated and reviewed, and the resulting exchange remains as a record that can be accessed online by various individuals over a substantial period of time. However, the permanent nature of online communication raises concerns about the quality of the information being exchanged. The nature of online communication may predispose individuals to take experientially based information as fact, and uncritically apply it to their own situation. This is of particular concern for rare or chronic disorders, in which treatment options are limited. In addition, the confidentiality of information shared online is questionable. The public nature of online discourse means that individuals cannot be certain who has access to the information they share, and how and when others may use it.

In a qualitative analysis of an online breast cancer listserv, Sharf (1997) found that the exchange of information and personal views was the most common form of communication, and that most exchanges were grounded in experiential knowledge. Information requests and responses ranged from questions related to medications and diagnoses, to psychosocial issues such as how to best talk to small children about the disease and how and when women should tell new dating partners about a previous mastectomy. Similarly, in an empirical investigation of an online self-help group for people suffering from depression, Salem et al. (1997) found that experiential knowledge was the most common form of knowledge shared by participants. Members were over four times more likely to help one another by sharing knowledge they gained through their experience with a shared problem, than by providing professional or second-hand professional knowledge.

Social Support

Self-help group members provide peer-based emotional and social support to one another. Genuine empathic understanding can buffer the impact of stressful circumstances by relieving feelings of stigma and isolation, and providing opportunities to discuss difficulties with others who truly understand (House, 1988; Madara, 2000; Thoits, 1986). Duke University researchers studied the value of

social support to the life expectancy of cardiac patients, and concluded that support groups may be as effective as costly medical treatments (Madara, 2000). In addition, the feeling of belonging that is engendered when connecting with peers who share similar experiences can create a strong sense of affiliation and community (Hyndeman, 1996).

Dunham et al. (1998) investigated social support processes in a computer-mediated network for single, young mothers, and found that the majority of the support exchanged was emotional in nature (56%). The researchers also used a pre-post scale to measure level of parenting stress in the mothers, and found that mothers who participated most consistently in the group were more likely to report reduced levels of parenting stress following the intervention.

Unlike face-to-face groups which have structured meeting times, the online environment provides access to support 24-hours a day. Individuals are able to connect to others when they are feeling most alone, such as in the middle of the night or at times when they are not able to get out. The online environment also has the unique potential to be "a secret world" that participants share, and it can serve to downplay or erase hierarchies that may exist among group members (Madara, 1997). Race, gender, ability, etc. disappear online. All members are equally connected to one another and traditional hierarchies are non-existent.

The built-in anonymity inherent to the Internet may also overcome disclosure and reluctance barriers that some people experience in face-to-face interaction. For many people, frank and open discussion about a sensitive topic, like sexually transmitted infection, would not be possible in a face-to-face environment. Although many face-to-face groups such as Alcoholics Anonymous operate on a first name basis to respect anonymity, in some circumstances true anonymity is not possible. In rural settings, for example, face-to-face groups in which a person uses their first name may not be anonymous, given small populations and a close-knit community.

In a qualitative analysis of an online group dealing with issues of disability, Finn (1999) found that a large proportion of messages involved self-revealing, catharsis, and discussion of personal and emotional issues. Self-disclosure state-ments were also found to be the most common type of interaction in an online discussion group for individuals with depression, occurring in 51% of the postings (Salem et al., 1997). The researchers contrasted this finding with a study of a similar face-to-face group (Roberts et al., 1991) in which disclosure statements occurred in only 7% of the comments.

Despite the potential of overcoming reluctance related to personal disclosure, some researchers have questioned whether the displacement of the online environ-ment may limit the ability to truly know and connect with others (Hyndeman, 1996; Madara, 1997). In face-to-face groups, one's whole person is present. Online you can share as much or as little of yourself as you want. Perhaps more importantly, physical connection and support is not available in an online environ-ment. It is necessary to question whether serious components of support are

lost due to the lack of physical, embodied interaction. In addition, the absence of physical and visual cues may lead to communication difficulties and misunderstandings when messages are misinterpreted or misread (White & Dorman, 2001).

Empowerment and Advocacy

Self-help ideology fosters empowerment through the inherent ownership and valuing of the group's agency and experience, allowing members to gain a sense of control in coping with difficult situations (Wallerstein, 1992). Group members take more active roles than the traditionally passive roles assigned to individuals as patients and consumers of health care. By taking part in self-help group initiatives, individuals are making conscious, responsible attempts to address their problems, experiences and emotions. In addition, self-help group members also take on active roles as sources of information and help for others.

An important concept in self-help ideology is the principle of "helper therapy" developed by Reismann (1965). That is, helping others can be even more beneficial than receiving help or support. As Madara (2000) states, "if you help someone up the hill, you get closer to the top yourself." The connection afforded through new technologies can be strong avenues for empowerment, given the ability of the Internet to link large numbers of people from diverse places and backgrounds. Individuals can gain knowledge and legitimization of their concerns through the identification of similar people who share their experience, in the form of a "strength in numbers" phenomenon.

The key to empowerment in self-help endeavors, whether online or face-to-face, is the valuing of experiential knowledge as important and worthwhile (Madara, 2000). Often this valuing is difficult to achieve, particularly within scientific and medical discourses (Schubert & Borkman, 1994). The conflict between professional and experiential knowledge plays itself out in a unique way online, given ongoing concerns over the regulation and quality of health information on the Internet (Cline & Haynes, 2001; Lindberg & Humphreys, 1998). There is often a push toward some level of professional involvement online, particularly for health related Websites, or at the very least a stamp of approval from an organization rating Websites based on predetermined measures of quality control. In the eyes of many, however, such professional involvement strikes at the very heart of self-help endeavors, and their ability to empower participants, as professionals can threaten group ownership and/or co-opt group processes (Hyndeman, 1996; Madara, 1999).

Despite concerns related to co-optation and control, professional involvement does have the potential to be helpful in self-help situations. Professionals can provide important perspectives and valuable information. Putting experiential knowledge in the context of professional, scientific information can be useful to participants, and can often clear up ambiguities or questions participants have. Some self-help groups have worked with professionals in joint learning,

education, treatment, and research development efforts (Madara, 2000). To this end, computer networks can be used as a forum for doctors and patients to communicate in more collaborative ways, and to gain a better appreciation of one another's perspectives and priorities.

In addition to the personal empowerment of group members, awareness-raising and advocacy endeavors often grow out of mutual support initiatives. When people with a common concern connect with others who share their experience, they are often empowered to work together to make a difference in relation to their cause. The potential of the online environment to act as a tool for connection and collaboration can make it an effective setting for advocacy work. Members of an online self-help group for survivors of breast cancer, for example, use their listserv to announce fund-raising events, art exhibits, and rallying cries for political response (Scharf, 1997). The Internet provides the opportunity to coordinate advocacy efforts, as well as to sustain and build on such efforts. In a qualitative investigation into how individuals coping with HIV/AIDS use the Internet, research participants describe the online environment as a particularly efficient forum for advocacy work, given the timely ability to connect with others over a current issue, such as legislation (Reeves, 2001). In particular, the written nature of communication online can create a transparent medium, which may help groups to stay on track and hold each other accountable. In essence, the online area becomes a "living record" which all participants can refer and have access to.

However, in self-help situations there can be a negative aspect to advocacy initiatives if a focus on advocacy deflects the group from their original sharing and supportive role. To some degree this danger is mediated online by the fact that individuals can choose whether or not to become involved in advocacy-type endeavors, by choosing which threads or messages they will pay attention and respond to. Such choice is only genuine in so far as it is available. If advocacy-type concerns overcome the majority of members in an online group, the supportive functions of the group may suffer.

INTEGRATING TRADITIONAL AND ONLINE FORMATS

Despite the above discussion contrasting the two approaches, online and face-to-face self-help need not be considered "either/or" possibilities. Although there are inherent differences in the two approaches, they can work together, using technology as a tool for bridging gaps related to accessibility but not as a replacement for traditional groups. One example is when online groups are used to get a "taste" or a "feel" for self-help options. Due to the anonymity provided online, people can "try out" groups without the degree of disclosure or commitment needed for face-to-face alternatives.

The benefit of anonymity and access may be important early on in the development of a self-help network, but eventually the need for physical contact and emotional support may lead individuals to seek out face-to-face groups.

Technology can allow people to safely meet others online, and develop supportive relationships that can grow to involve interpersonal interaction. An advantage is that people can be in control of the pace and terms of such relationships to a greater extent when they develop online.

In addition, online opportunities can be seen as a supplement to face-to-face alternatives. Individuals may use both online and face-to-face forms of support at different times. For example, 3:00 A.M. a recovering alcoholic can log-on to a discussion group in order to get support needed to stay sober until they are able to call a sponsor or attend a face-to-face meeting. There may also be extended periods of time when ividuals cannot access traditional avenues of support, for example when illness prohibits attendance at face-to-face meetings (White & Dorman, 2001). At these times online support becomes an important and necessary alternative.

It is important not to view online and face-to-face approaches as mutually exclusive when considering the knowledge/gap hypothesis, the phenomenon that new technologies disproportionately benefit the well off and educated in society (Madara, 1997). An inherent danger lies in the possibility that online groups could supplant face-to-face alternatives, thereby reducing the number of options available and dictating who will have access to social support avenues and who will not. This concern calls for a balance in the use of new technologies, and also speaks to the need for increasing access to those who are not currently in a position to benefit from online options (Skinner et al., 2003). New and creative ways must be explored to achieve more representative access.

A possible limitation to online groups is the time it can take to wade through a large volume of messages that typify listserv or bulletin board discussions. Both Sharf (1997) and Salem et al. (1997) estimate that they spent roughly two hours a day reading online discourse. To derive full benefits from online sources of support, one must often set aside a great deal of time and be motivated to follow the discussion. This is a further argument for the integration of online and face-to-face approaches, for those who would find online options good tools in certain circumstances, but who do not have the time or commitment to rely on online groups as their main source of support. Viewing online and face-to-face approaches as dialectical in this manner allows one to capitalize on the benefits and moderate the limitations of both approaches.

RESEARCH NEEDS

Given the relative newness of information technology within the broad public domain, research into online self-help is in its infancy. Many challenges exist. For example, Dadich (2003) describes issues in conducting a study of young people with mental health issues. Flicker et al. (2004) outline three ethical predicaments in online research: 1) enrolling research participants; 2) protecting participants from risk or harm; and 3) linking public and private data.

   Table 2 highlights guiding questions for investigations into the role and potential for self-help online. In particular, conceptual models of self-help are needed,to understand differences and similarities between online and face-to-face approaches. Research is also needed into the composition of online self-help groups, and the resulting group dynamics. Who chooses to use online options, how are such choices made, and in what ways do these considerations affect the dynamic of online groups? Another important dimension addresses the debates regarding the quality of information online. How does the push for the regulation of online information affect the community ownership ideals of the self-help movement?

   The popularity of online self-help stands as a testament to the fact that online options are meeting specific needs (Madara, 1997). Online groups have the

Table 2. Research Needs

Area	Guiding questions
Conceptual models of online self-help	• What is the nature of experiential learning online? • What is the nature and potential for empowerment online? • Is there a difference between low-tech (e.g., e-mail) and high-tech/more interactive options (e.g., discussion boards)?
Social and emotional support online	• What is the level and extent of emotional support online? • Does the lack of face-to-face interaction impact upon sustainability?
Participation in online groups	• Are different kinds of people attracted to online groups as opposed to face-to-face alternatives? • What are the barriers to participation in online groups? • Which groups are represented online and which are marginalized?
Regulation of online information	• To what extent does the push for regulation pose a threat to the community-ownership ideals inherent to self-help? • How is experiential knowledge understood in an online context? • What is the impact of the regulation of commercial environments vs. non-governmental environments?
Integrating online and face-to-face self-help	• What is the current relationship between online and face-to-face approaches to self-help and social support? • What are potential relationships or models for realizing an online/face-to-face dialectic (integration)? • When do the approaches work together, and when do they work better as separate understandings?

potential to honor traditional self-help values related to information sharing and experiential learning, social support, empowerment, and advocacy in new and exciting ways. There are many benefits to the use of information technology for self-help and mutual support—including increased accessibility—and the potential to overcome barriers some people may experience in relation to self-disclosure and participation in face-to-face groups.

Ferguson (2000) argues that new technologies are uniquely positioned to usher community-based approaches like self-help along a new patient-driven wave in healthcare. "With the support of effective consumer health informatics systems, the old configuration will be replaced with a new Information Age healthcare system . . . (in which) people with a health concern or problem will begin by managing it themselves; they will move on to other resources only as needed" (Ferguson, 1995). There are, however, many important concerns, most notably related to the limited online access available to certain groups, particularly those who are marginalized and/or economically disadvantaged.

In conclusion, online groups have opened up a new frontier linking information technologies with traditional self-help/mutual support. The prospects are wide-ranging. However, integrative models and systematic investigations are needed to realize the full potential of online methods and minimize inherent drawbacks.

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