Fostering empowerment in online support groups

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Abstract

Online support groups have been used extensively, in numerous areas of distress, for 15 years. Researchers have presented conflicting findings and ideas about their effectiveness in helping people cope with respective problems. Our review of quantitative studies and our qualitative exploration of the nature of the experiences that occur in such groups show that several factors operate to potentially affect participants. Personal and interpersonal dynamics, which are central in producing effects in these groups, are induced and accelerated by the powerful online disinhibition effect. These factors, including the very impact of writing, expressions of emotions, collecting information and thereby improving understanding and knowledge, developing social relationships, and enhancing decision-making skills and consequent behavioral actions all serve as possible generators of a sense of personal empowerment for people in distress. This view may explain why empirical research has frequently found little or no specific outcomes from participating in online support groups; however, it has found much support for nonspecific personal impacts of this means of intervention. Thus, we contend that online support groups are designed to foster, and many of them actually do, well-being, a sense of control, self-confidence, feelings of more independence, social interactions, and improved feelings—all nonspecific but highly important psychological factors. As such, participating in an online support group could foster personal empowerment, which is much needed in handling specific conditions of distress. Nonetheless, this participation has potential costs, too, especially developing dependence, distancing from in-person contacts, and exposure to unpleasant experiences typical of social engagement in cyberspace.

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1. Introduction

Support groups have a long history. They seem to have been in existence hundreds of years ago in fraternal organizations such as Freemasonry, but their popularity began blooming in the middle of the 20th century when Alcoholics Anonymous and other 12 Steps movements showed that group support was essential in helping members recover from a distressful situation and obtain some emotional relief. These groups based themselves on the simple premise that people who share similar difficulties, misery, pain, disease, condition, or distress may both understand one another better than those who do not and offer mutual emotional and pragmatic support. Over the years, the special value of social support to an individual’s well-being, emotional state, and perceived self-efficacy has been recognized in the context of formally established groups, as well as informally in the natural social environment (Farris Kurtz, 1997; Sarason, Sarason, & Pierce, 1990). A significant shift in people’s recognition and focus on social support emerged as they acknowledged that a support group was an inexpensive, convenient, yet effective vehicle for obtaining help. The self-help trend integrated into support groups and has gained much empirical support as numerous investigations and personal testimonies have evidenced (see a comprehensive review by Tucker-Ladd, 1996–2006).

Online support groups began to emerge in the 1990s. Less accepted by the professional society, they gained only sporadic publication on the Internet and a few early reports at conferences (see King & Moreggi, 1998). This movement, however, has now grown into a mass social phenomenon that is estimated to number hundreds of thousands such groups worldwide. Online support groups can operate through various Internet applications—an email list, a chat room, or a forum (“bulletin board”), but it is the last form that seems to have become the overriding technology, as participants take advantage of its asynchronicity as well as of various other features: easy access, opportunity for archival search, convenient use of emoticons and links, and friendly design (Meier, 2004).

Online support groups exist on practically every distress topic possible, from patients with asthma to parents of children with autism, from hearing-impaired adolescents to children with Alzheimer disease parents, from victims of rape to dyslectic students, from early divorcees to patients dying of a particular type of cancer, and from socially phobic adults to smokers who are trying to quit. For those who take part in an online support forum, the group functions as a durable and accountable help resource through which they transmit and obtain information, provide and receive emotional support, socialize and form interpersonal relationships, and experience comradeship with others sharing a similar distress, thereby helping to reduce their perceived anomaly (Bane, Haymaker, & Zinchuk, 2005). It is important to note that despite obvious similarities and though frequently there is a lack of differentiation between them (Bellaïfiore, Colôn, & Rosenberg, 2004; Colôn & Friedman, 2003; Mallen, Vogel, Rochlen, & Day, 2005; Meier, 2004), a support group differs substantially from a therapy group. Several core differences should be noted: first, unlike a therapy group, no pre-planned, targeted professional manipulation—a treatment protocol—is conducted or delivered in support group. Second, the purpose of support groups is basically to offer relief and improved feelings rather than therapeutic change in the emotions, cognitions, or behaviors of participants. Third, support groups may operate without a leader or manager or have a nonprofessional administrator, whereas therapy groups always have trained professionals who lead them. Fourth, a support group is usually an open forum, which participants can join or leave at anytime, whereas a therapy group
is seldom open. Fifth, and related to the previous characteristic, support groups last without specific time limits, and indeed they may last continuously, whereas therapy groups are usually time-limited.

Support groups, including their online version, are not a substitute for the treatment of any kind of distress. A common mistake, or myth, holds that a good support group might replace therapy. The argument made here, however, is that participation in a support group—perhaps even more so in an online support group—might in many cases provide added value to standard therapy, counseling, or professional care or any kind, as this means of emotional support has the great potential to contribute to participants’ sense of personal empowerment. As such, online support groups might be considered a possible supplement to more traditional professional treatment; their contribution lies more in affecting people’s general well-being than causing therapeutic change.

2. The concept of personal empowerment

Empowerment refers to a concept imprinted several decades ago in the context of strengthening minority groups. Despite its ambiguity and lack of a coherent and broadly accepted definition among professionals (Ackerson & Harrison, 2000), it seems that theory and research have developed a substantiated conception of the term. Many researchers view empowerment as multidimensional, noting its various spiritual, social, organizational, economic, political, and psychological dimensions (Berton, 1994; Cowger, 1997; Rappaort, 1987). The concept has broadened, however, by adopting it to individual processes rather than limiting it to a group’s status. In the individual framework, empowerment entails several personal factors that are experienced, including the ability to make personal decisions, to exercise critical thinking, and to access relevant resources (Wallerstein, 1992). Basically, as Boehm and Staples (2002) explained, the concept of empowerment refers both to the “power to”, which “involves an individual’s ability to act efficaciously to bring about desired results”, and to the “power over”, in the meaning that “A exercises power over B when A affects B in a manner contrary to B’s interests (Lukes, 1974, p. 27).” In addition, empowerment refers to experiencing personal growth as a result of developing skills and abilities along with a more positive self-definition (Staples, 1990).

In other words, empowerment entails both perceived capabilities in coping with various challenges and the perceived ability to overcome obstacles. Thus, emphasis is placed on the process of self-perception, as well as on anticipated outcomes—that is why the term a “sense of empowerment” describes an experiential mental state rather than an objective condition.

It is important to note that Dickerson (1998), in reviewing strategies that foster personal empowerment, especially in the context of mental health-related disabilities, acknowledged that self-help or mutual-help groups are among the most effective vehicles to promote the concept. This is apparently so because support groups are directly associated with three main attributes of personal empowerment: first, reliance on self and peers rather than on authoritative professionals contributes to gaining a sense of personal competence. Second, voluntary participation and free choice that relate to decisions and planning contribute to feelings of self-determination. Third, helping others and socially identifying with others (such as in regard to anger about stigma) contribute to perceptions of social engagement. Dickerson’s and other, more recent views on the importance of self-help groups in fostering empowerment in the context of mental health (e.g., Fitzsimons &
Fuller, 2002) and health in general (Korp, 2006) are obviously strengthened in light of the current acceptance and widespread use of online support groups. This view also integrates well with the outlook that empowerment basically focuses on self-care; that is, handling and coping with emotional difficulties independent of professional and establishment involvement (O’Cathain et al., 2005). In any attempt to comprehend how a sense of empowerment may be generated in the context of online support groups, therefore, it seems rather important, to understand the special mechanisms that operate and the processes that take place in the dynamics of such forums.

3. Disinhibition effects in online support groups

It is well known that people say and do things in cyberspace that they ordinarily would not say or do in the face-to-face world. They loosen up, feel more uninhibited, and express themselves more openly. Researchers call this the online disinhibition effect (Suler, 2004a; Suler, 2004b).

The impact of this disinhibition effect on an online support group can be positive or negative (Tanis, 2007; Tanis & Postmes, 2007). Because honesty and self-disclosure are such important therapeutic ingredients of such groups, the disinhibition effect can accelerate its salutary functions. Group members might share very personal thoughts or disclosures about themselves and their lives. They might reveal secret emotions, fears, or wishes; they might show unusual acts of kindness and generosity. As a result, interpersonal intimacy and group bonding develop. However, the disinhibition effect may not always be so benign. It can also lead to rude language, harsh criticisms, anger, hatred, and even threats. Some group members might act out in ways that disrupt the group’s cohesion. For other people, self-disclosure and intimacy might develop too rapidly, resulting in regret, anxiety, and a hasty termination of membership in the group. On the positive side, disinhibition indicates an attempt to understand and explore oneself, to work through problems and find better ways of relating to others. On the negative side, it may be simply a blind catharsis, an acting out of unsavory needs and wishes without any personal growth at all.

What causes this online disinhibition? Several factors are in operation, many of them driven by the qualities of text communication. For some people, one or two of these factors produce the lion’s share of the disinhibition effect. In most cases, these factors interact, supplementing one another and resulting in a more complex, amplified effect.

3.1. Anonymity

In an online support group, people do not necessarily know one another’s identities. People only know what the other people choose to reveal about themselves. Clearly, anonymity has played an important role in the history of many 12-step programs (classic group interventions targeting especially alcoholism and addictions, but also other behavioral problems, based on a set of guiding principles for recovery that included 12 phases), with participants feeling a level of safety in the group that enables them to self-disclose. Online support groups can carry that anonymity to a new level. When people have the opportunity to protect their real world identities from the occurrences within the group, they feel less vulnerable about participating and opening up. Whatever they say or do cannot be directly linked to the rest of their lives. Group cohesion and trust develop from this reassuring knowledge that what happens in the group stays in the group (Christopherson, 2007).
3.2. Invisibility

In the text-communication format that is common to almost all online support groups, people cannot see one another. They may not even know that a particular person is present. Invisibility gives people the courage to say things that they otherwise might not. This power to be concealed overlaps with anonymity, the concealment of identity, but there are some important differences. In text communication, people might know a great deal about the identity of others, but they still cannot see or hear these others, which amplifies the disinhibition effect (Suler, 2004b). Group members do not have to worry about how they look or sound, which is an especially powerful facet of disinhibition in groups that address personal problems affecting physical appearance or speech. Also, there are no frowns, shaking heads, sighs, bored expressions, or other subtle and obvious signs of disapproval and indifference that would otherwise inhibit people. In everyday relationships, people sometimes avert their eyes when discussing something personal and emotional. It’s easier not to look into the other person’s face. Text communication offers a built-in opportunity to keep one’s eyes averted.

3.3. Delayed reactions

In the asynchronous communication of some online support groups, people may take minutes, hours, days, or even months to reply. Not having to worry about an immediate reaction can be disinhibiting. Immediate, real-time feedback from others tends to have a powerful effect on the ongoing flow of how much people express. In e-mail and discussion-board groups, where there are delays in that feedback, a person’s train of thought may progress more steadily and spontaneously toward deeper expressions of what one is thinking and feeling. Some people may even experience asynchronous communication as an opportunity to temporarily “get away” from the group after posting a message that is personal, emotional, or hostile. The freedom to leave and reenter the group can help people therapeutically manage the emotions that the group process stimulates, thereby encouraging disinhibition (Taylor & MacDonald, 2002).

3.4. Solipsistic introjection

In text communication, a group member sometimes feels that his/her mind has merged with the minds of other members of the group. Reading another person’s message might be experienced as a voice within one’s head, as though that person has magically been inserted, or introjected, into one’s psyche (Suler, 1999; Turkle, 1995; Turkle, 2004). Consciously or unconsciously, people assign a cognitive representation to how they think others look and talk. Another group member then becomes a character within one’s intrapsychic world, a character that is shaped partly by how the person actually presents him- or herself via text communication, but also by revealing ones expectations, wishes, and needs. As the character now becomes more elaborate and real within one’s mind, a group member may start to think, perhaps without being fully aware of it, that the typed-text conversation is all taking place inside one’s head, where it is safe to say almost anything. This process might involve transference reactions, which can cause a disruption of interpersonal understandings within the group. However, solipsistic introjection can also enhance empathy, bonding, and the identifying with other group members that is critical in a support group, especially if
the group understands and knows how to work with these transference distortions, which are common in text communication.

3.5. Neutralizing of status

In online support groups, people do not see the trappings of status and power—the fancy office, expensive clothes, diplomas on the walls, or books on the shelves. They do not necessarily know about one another’s “position” in the face-to-face world. In addition, a long-standing attitude on the Internet has been that everyone should be equal; everyone should share; everyone should have equivalent access and influence. Respect comes from one’s skill in communicating, the quality of one’s ideas, and one’s integrity as a person. Everyone, regardless of status, wealth, race, or gender, starts off on a level playing field. Combined, these factors tend to reduce the perception of authority that can inhibit people from speaking their minds (Galegher, Sproull, & Keisler, 1998). The neutralizing of status that encourages people to self-disclose is especially important in online support groups, which historically have emphasized peer-to-peer assistance rather than reliance on professionals or other authority figures.

Of course, the online disinhibition effect is not the only factor that determines how much people open up or act out in cyberspace. The strength of underlying feelings, needs, and drive level exerts a big influence on how people behave. Personalities also vary greatly in the strength of defense mechanisms and tendencies toward inhibition or expression. People with histrionic styles tend to be very open and emotional. Compulsive people are more restrained. The online disinhibition effect will interact with these personality variables, in some cases resulting in a small deviation from the person’s usual behavior and in other cases causing dramatic changes.

The online disinhibition effect is a powerful mechanism that operates in interpersonal interactions in cyberspace, influencing people to act in ways they apparently would not have acted in their physical environment. In online support groups, as discussed above, this might have productive or detrimental value. Other unique factors characterizing online support group participation, however, may navigate the virtual experience in more positive directions.

4. Personal empowerment processes from participation in online support groups

Research has indicated that various processes that take place in online support groups, owing to both the very participation and the outcomes of this participation, may generate the experiencing of personal empowerment. This personal sense may emerge from the act of writing itself, which enables emotional outlet and a sense of cognitive order; from emotional relief and catharsis; from receiving and providing necessary information; from interpersonal interactions and the formation of relationships, thereby reducing isolation; and finally from acquiring self-confidence and reassurance, which allows better decision-making and behavioral transformation. The paragraphs to follow look more closely into these factors.

4.1. Psychological impact of writing

Writing may be used to achieve a sense of relief by exposing one’s most inner feelings, which can lead to emotional catharsis. Through writing, the writer explores core
experiences and names them, which allows the possibility of obtaining a sense of determination and meaning. This process helps writers understand themselves and their own experiences in a clear and organized way, while balancing emotions and thoughts. The clarity achieved by writing gives one a sense of empowerment and control over one’s life (Pennebaker & Seagal, 1999). Consistent with these arguments, writing about feelings and experiences associated with difficulties has been found to decrease negative emotions and increase positive ones, whereas writing about neutral events has no such effect (e.g., Esterling, L’Abate, Murray & Pennebaker, 1999). Thus, for many people, writing is a factor that can be considered a generator of personal empowerment.

For example, in a study that analyzed participants’ storytelling in a Scandinavian breast cancer online support group consisting of 15 women, Hoybye, Johansen, and Tjornhoj-Thomsen (2005) found that participants, by sharing personal stories with others in the group, were actively portraying their life stories and identities. The shift from being acted upon to being active in inter-subjective storytelling and taking charge of themselves through the written word results—as these researchers reported—in an elevated sense of control and empowerment.

Writing provides a form of expression that enables individuals to present their authentic and experiencing self. Through writing, the writer expresses thoughts and emotions that may not have been and are difficult to be exposed in other environments (Wright, 2002a; Pennebaker, 1997). Online support groups allow free and natural expression in writing in ways that fit individual preferences and abilities, whether taking the form of poems or stories, whether straightforward prose or metaphors (Hoybye et al., 2005; Hsiung, 2000). Moreover, writers may use various tones to communicate, choosing the one that is most compatible and comfortable at the time, be it humor, cynicism, frustration, or grief. For example, in the Scandinavian breast cancer support group, participants shared the difficulties they encountered both in a more serious manner and through humor and jokes; some of the postings were designed to elicit laughter, and this often led to the relief of tension. A similar pattern was observed in other online support groups, such as for persons with disabilities (Braithwaite, Waldron, & Finn, 1999). Thus, the ability to communicate and describe personal difficulties and handicaps, and even to laugh about them, seems to induce a sense of personal empowerment by bringing about emotional relief and a better sense of control.

4.2. Expression of and connecting to emotions

Participation in a dynamic group entails a process of creating intimate interpersonal connections. This increases social cohesiveness, thus legitimizing the expression of a variety of feelings (Bakardjieva, 2003). Lieberman and Goldstein (2006), who examined the level of expression of negative emotions in an online support group of breast cancer patients, found the ability to convey negative feelings as being imperative to the improvement of well-being and the quality of life.

It is apparent that sharing bad feelings with others has a tremendous relieving effect. Consequently, group participants feel better when they can share their difficult emotions with others who listen to them and understand them. As exemplified and described by members of a dental anxiety online support group, the mere articulation of a participant’s personal story leads to a cathartic experience, which brings on emotional relief (Buchanan & Coulson, 2007). In another example, similar experiences were observed in an online
support group for people with hearing disabilities. Participants in this group, who previously lacked social support and felt alienated and oppressed, felt enriched from the emotional perspective of taking part in a support group all of whose members had a similar impairment (Cummings, Sproull, & Kiesler, 2002). Emotional relief and emotional bonding lead to a sense of betterment, and subsequently to a feeling of personal empowerment and improved self-confidence.

When a support group is designed to target a specific issue, there is typically the feeling of a common language that need not be explained or justified. This is often the case when dealing with people who have little understanding of the difficulties in question. Therefore, sharing personal stories, as well as reacting to the personal stories of others, is communicated within the group with much empathy, alongside emotional reinforcements and sincere support. Typically, reaching out to the members of a support group is induced by a desire to belong to an entity composed of people with similar issues. Eventually, that feeling of belonging becomes the reason for remaining a part of the group while providing needed support to others (Radin, 2006; Tanis, 2007). The feelings of belongingness and togetherness are crucial and significant, and contribute to personal empowerment (Bakardjieva, 2003; Tanis, 2007).

4.3. Impact of information and knowledge

A sense of personal empowerment is often achieved by acquiring relevant information and knowledge, especially if they are obtained directly from available resources and not through an authoritative, filtering agent. This sense clearly relates to another dimension of personal empowerment: the ability to make personal decisions through direct access to relevant resources. Indeed, many turn to an online support groups in search of information related to their area of distress in the belief that acquiring information will give them a better understanding of what they are facing and more knowledge of how to handle it. However, it seems that it is not only the access and exposure to information as such that empowers people; it is also their very ability to share information with others. It is, then, not only the receiver but also the provider of the information who is empowered, the latter by taking the role of guide, instructor, and helper. Conveying information that contains guidance or recommendations changes the information-provider into someone who is active and who possesses a vital and valuable experience (Bakardjieva, 2003). This subsequently empowers the information receivers and transforms them from being dependent and passive to active participants who demonstrate strength and power. These effects were demonstrated in a variety of online support groups, such as for breast cancer (Hoybye et al., 2005; Radin, 2006), physical disabilities (Braithwaite et al., 1999), food allergy (Coulson & Knibb, 2007), hysterectomy (Bunde, Suls, Martin, & Barnett, 2007), clients in therapy (Zuckerman, 2003), multiple sclerosis (Weis et al., 2003), and child care (Worotynec, 2000).

Braithwaite et al. (1999), who analyzed messages from a group of people with (mostly physical) disabilities, found that information was a central component in providing support and constituted the second most common category among existing social support categories. The type of information they referred to included advice, referral, situation appraisal, and teaching. Messages coded as informational support appeared to reduce uncertainty and helped make life more predictable. Reducing uncertainty was seen to be significant in groups of breast cancer patients who were exposed to survivors’ stories.
The information communicated through these writings created hope and provided encouragement (Hoybye et al., 2005). It is important to note that—against common beliefs—that in many cases the information provided by lay people in online support groups is not erroneous or harmful (e.g., Hwang et al., 2007).

Typical of many support groups, discussions often deal with coping strategies (e.g., Coulson & Knibb, 2007; Braithwaite et al., 1999; Buchanan & Coulson, 2007). In some cases, receiving information and guidance from fellow participants, who either have endured similar difficulties themselves or perhaps live with or are otherwise close to someone with this difficulty, is much more significant, and more easily accepted, than receiving the information from a professional. The application of information on coping mechanisms is perceived as giving encouragement and providing hope to group members, as well as confidence in their ability to feel better and to adapt to the new realities of their lives (Buchanan & Coulson, 2007; Wright, 2002b).

4.4. Effects of interpersonal relationships and social processes

Many individuals use their participation in an online support group to reduce feelings of loneliness and social isolation. This can especially be relevant for people who suffer from a stigmatized physical or mental condition or who feel inferior because society does not accept their special identity. For instance, people with disabilities may have great difficulty in mobility, making it difficult, and at times impossible, to join a face-to-face support group or other social gathering and thereby leading to feelings of social isolation. Many members of ethnic minority groups, not only ethnic but also new immigrants, homosexuals, and people with certain diseases experience similar feelings. The Internet provides access to support groups with no physical barriers and an opportunity to interact socially with others who share a similar condition. Taking part in an online support group provides participants with a sense of belonging, affiliation, and social cohesion, which subsequently translates into feelings of personal empowerment (Braithwaite et al., 1999). A typical example is someone with a food allergy. Participants in the group dedicated to such problem have revealed feelings of isolation, incompatibility, and a difficulty in confiding in friends and family members. They could, and did, however, find the solidarity and understanding for which they were looking through the online support group to which they belonged (Coulson & Knibb, 2007). The group, then, becomes a communal, safe, and non-judgmental virtual location for individuals who feel isolated and different (Wright & Bell, 2003). Similar findings have been detected in empirical research on online groups offering support relating to specific issues, such as siblings of children with special needs (Tichon & Shapiro, 2003), adults with ovarian or prostate cancer (Sullivan, 2003), those with multiple sclerosis (Weis et al., 2003), child care (Worotynec, 2000), and diabetes (van Dam et al., 2005). In all of these cases, as well as in many others, participants highlighted social closeness as a major factor in giving them a feeling of relief. It is important to note—in response to a common argument raised in this context—that feelings and attitudes relating to social interactions generalize from online to offline situations (Bagozzi, Dholakia, & Pearo, 2007); thus, a sense of empowerment is developed in online support group participants in relation to their offline social relationships, as well.

In their study of a dental anxiety online support group, Buchanan and Coulson (2007) found that feelings of personal empowerment were a result of communication within the group, which allowed participants to feel sufficiently safe and secure to reveal their
difficulties. A-priori feelings of isolation, frequently experienced by group members before joining, had prevented them from exposing their emotions at first. However, once the group coalesced and produced a sense of assurance among its members, and consequent confidence in sharing with one another, feelings of personal empowerment and growth emerged. It became apparent that the participants in this support group felt they could communicate their hardships and receive support without risking rejection or distancing they typically experienced in their offline environment. Another interesting example is a support group offered to Canadian aboriginal women (Hoffman-Goetz & Donelle, 2007). On top of the benefits these women—isolated and disconnected from effective resources—received from participation in a chat room-based support group, the investigators underlined social cohesion and close interpersonal relationships in the more general context of health care.

4.5. Influence on decision-making and resulting action

Individual decision-making is enhanced through discussions in an online support group because participants learn more sophisticated ways of gathering information, gain a better understanding of the nature of their distress, develop enhanced considerations in regard to relevant and important factors in the handling of their condition, and learn from the experiences of others. In a breast cancer online support group, Sharf (1997) found that communication within the group fostered reexaminations of decision-making processes. Discussions among group members challenged participants to rethink and reevaluate their prior decisions, attitudes, and courses of action in regard to coping with their emotional, social, and practical difficulties. The process of rethinking and reevaluating provided greater understanding of relevant issues and more confidence in taking action. Other examples of influence of participation in online support groups on decision-making and consequent action include making dentist appointments after participating in a dental anxiety online support group (Buchanan & Coulson, 2007), obtaining a second opinion following participation in a breast cancer support group (Hoybye et al., 2005), developing decision-making skills in reexamining optimal choices of action in relation to prostate cancer (Seale, 2005), and gathering effective and practical information in a support group for women in midlife transition dealing with menopause (Bresnahan & Murray-Johnson, 2002).

The review presented above is based mostly on quantitative studies, in which the effects of participating in an online support group and the processes participants go through were evaluated by questionnaires, verbal behavior analyses, and other measures. The experiences of these participants may be investigated through a different, more phenomenological approach, however. The two perspectives would then provide a broader view of the issues in question.

5. Pros and cons of participation in online support groups: lessons from eQuest

Our evidence and discussion of the psychological processes that take place in online support groups can be complemented significantly and promoted by a qualitative-experiential investigation. In the psycho-educational program known as “eQuest”, people engage in a variety of online activities in order to gather information, better understand, and hopefully resolve some personal issue in their lives—for example, issues related to
suicide, alcoholism, divorce, self-injurious behaviors, Alzheimer’s, ADD, and grief (Suler, 2005). One such activity is to find and participate in an online support group that addresses the issue that the eQuest participant is exploring. The experiences of people who have completed the eQuest program reveal some of the pros and cons of such groups insofar as affecting their sense of empowerment in resolving their respective particular issues.

Given that there are thousands of online support groups, finding a helpful one can be hit or miss. The sheer number of groups is daunting, especially to people who are not knowledgeable about searching the Internet. Some groups present vague or inaccurate descriptions in web page listings. Many are small or inactive, while others may seem overwhelmingly large and busy. Although there seem to be support groups covering every imaginable topic, a person may still experience difficulty in locating a group devoted to a particular issue, especially issues that are rare or very specific, but sometimes even those that are fairly common. For example, one eQuest participant, a college student, could not locate a group that addressed the topic of test anxiety.

The next challenge after joining a group is to evaluate whether it is appropriate and, if so, to integrate oneself into it. Participants in eQuest are encouraged to quietly observe a group for a week or more to gain a sense of its members, of how it functions, and of its norms regarding appropriate and inappropriate behavior. Doing so will help the person decide whether to stay in the group and how to introduce oneself to this forum. The first post to the group can be a crucial step in the integration process and should be considered carefully. Whether the group offers a warm and supportive reception to that first message, responds with criticism or an off-putting comment, or completely ignores the message can have a big impact on a newcomer. The newcomer should consider friendly, unfriendly, or mixed reactions as possible indicators of deeper dynamics within the group. Because the personality and operations of online groups differ widely, even among groups devoted to the same issue, eQuest participants are encouraged to “shop around” to find a group that is the best fit for themselves. For example, some people may decide that they have a decided preference for groups that employ synchronous communication. Others might decide that they simply do not like any type of group that relies on text communication. In the end, eQuest participants are instructed to trust their “gut” reaction to all aspects of the group experience. If something about a group does not feel right, leave it.

Once they have joined an appropriate group, eQuest participants report experiences about the pros and cons of an online support group not unlike those of in-person support groups. It takes time to feel comfortable about participating and to develop a coherent image of the different group members in an online group, more so than in a face-to-face group, where visual appearances help solidify one’s impressions of others. Participants have reported problems in identifying with other online group members who seem very different from them. Many appreciate the level of sharing they experience in the group, the support members offer one another, the lack of criticism and judgment, and the diversity of information related to the issue being discussed. They are impressed by the variety of personal perspectives that group members bring to the group; this is often a by-product of the group’s being online, since it is then able to draw members from diverse geographic and socio-economic locations. Some worry that typifies to offer the group. Often the stories told by particular people have a big impact on them, usually by those with whom they identify or people who are mastering dire versions of their own situation. Despite the diversity of people, backgrounds, and experiences being discussed in a group, the eQuest
participants were most impressed by the therapeutic factor, which plays such a critical role in all support groups: the realization that other people share the same difficulty, that one is not alone in struggling with a problem. Some eQuest participants, who did not fully understand the potential power of online support groups, were surprised or caught off guard by the intensity of their emotional reactions to experiences within the group. Curiously, almost all of the eQuest participants, who were college students, although quite active in cyberspace, knew very little about online discussion groups. As such, the support groups were a new experience for them.

Aside from the group itself, eQuest participants were also influenced significantly by one-on-one relationships that they developed with other group members. Contact with participants outside the group, usually by email, helped them on a more intimate level of sharing, while also assisting them in better understanding and adapting to the group as a result of mentoring from these participants.

In some cases, eQuest participants were concerned about the beliefs and information promulgated by their groups. One college student, who had taken a course on autism, questioned some of the “facts” about autism endorsed by a group devoted to this issue, resulting in a negative response from other members. Another person, a “cutter” who wanted help with her self-injurious behaviors, worried that detailed descriptions of the stress-reducing aspects of cutting might trigger members into pursuing this activity. She also perceived another group as endorsing and perhaps even idealizing cutting as a type of fashion statement, not unlike various types of body piercings.

Such reports point to phenomena that deserve careful study by researchers of online support groups. Although the emphasis on peer-to-peer help can be very therapeutic, some support groups might develop blind spots and promote misinformation if they are too rigorous in rejecting professional knowledge. They might reinforce a maladaptive belief system when selecting or reinterpreting findings from the body of scientific research. Blatant hostility toward authorities and the stifling of opposing ideas within the group may be symptomatic of an overly rigid belief system. Research on “ideology” in successful self-help groups suggests that each group develops its own particular system of beliefs and attitudes that serve as an antidote to the maladaptive beliefs and attitudes that perpetuate the particular problem shared by group members (Antze, 1976; Suler, 1984). The vast number and types of online support groups provide a fortuitous opportunity for researchers to study the role of ideology in support groups, including how people join groups that either reinforce or remedy the maladaptive beliefs underlying their problem and how groups may develop different therapeutic ideologies that address the unique needs of their particular members or the unique aspects of a specific variation of the problematic issue.

6. Specific and nonspecific effects of online support groups on participants: an overview

It seems that the basic factors identified by quantitative research, as well as by our qualitative study—impact of writing, expressing emotions, gathering information and improving knowledge, developing interpersonal relationships, and bettering decision-making skills—generate, each and all of them, a personal sense of empowerment. This outcome of participation in an online support group, however, refers to a general rather than a specific effect that is typifies of a successful support group. In other words, while we expect therapeutic treatment to cause specific effects—durable changes relevant to a problem in
question—a support group is not expected to produce such outcomes but, rather, to contribute to participants’ general well-being.

Consistent with our observations, the review of research on the effects of online support groups on participants—dealing with various areas of distress, populations, and communication modalities—reveals that such groups are not necessarily effective in terms of producing therapeutic change. As stressed earlier, this finding is not surprising for those who understand that support groups do not substitute for professional treatment and do not pretend to create substantial change in factors related to the nature of the distress. Actually, support groups might offer a complementary component of therapeutic change (Davison, Pennebaker, & Dickerson, 2000; Meier, 2005; Norcross, 2006). This conclusion concurs with a comprehensive review of the effectiveness of health-related online support groups that was conducted by Eysenbach, Powell, Englesakis, Rizo, and Stern (2004), who found little support for the effectiveness of online groups in terms of outcome measures (such as depression). Although their research was criticized on various grounds (Barak, Grohol, & Pector, 2004; Potts & Ramirez, 2004), it seems that its major limitation lies in the very conception of support (in contrast to treatment). That is, taking part in an online support group does not aim at effectiveness in terms of distress-related outcomes; rather its objective should be seen in terms of affording general emotional relief and an elevated sense of control—two essential components of personal empowerment. A similar argument can be made of another review, that of cancer support groups (Klemm et al., 2003), in which the researchers were looking for effectiveness in terms of specific, cancer-related condition outcomes. However, a review of social support in the area of diabetes by van Dam et al. (2005), including participation in online support groups, revealed that the impact of such support lay in participants’ acquiring more positive attitudes and subsequent behaviors related to their disease. That is, when evaluating the impact of a support group on participants in terms of general, nonspecific effects, findings show a quite different picture from conclusions that address therapeutic effectiveness. It is interesting to note that participation in an online support group as such does not constitute a sufficient condition for emotional relief or for fostering personal empowerment. Barak and Dolev-Cohen (2006) showed that, on the average, participants in an online support group for suicidal adolescents did not experience relief; this conclusion emerged from an unobtrusive analysis of their writings over three months. More active participants—in terms of responding to others and being responded to—were found, however, to gain emotional relief in comparison with more passive participants. This last finding might reflect a fact—that more active participation leads to greater personal empowerment; it also may explain why specific measures of effectiveness might not be relevant.

The basic argument that this article sets forth is that support groups—in contract to counseling and therapy interventions—primarily affect participants’ personal empowerment rather than bring about specific therapeutic changes. That is, while therapeutic interventions aim at producing tangible emotional, cognitive, behavioral, or physiological changes in individuals—linked to their respective area and severity of distress—support groups, in principle, lead to more general personal feelings. These feelings have to do with bettering a sense of self-control, with well-being, self-confidence, mood state, self-image, loneliness, optimism, and even with a sense of control over a disease (Broom, 2005)—and not necessarily with parameters that directly and concretely relate to the distress area in question. We thus argue that the impact of participation in online support groups may prove significant; however, research on this subject that
does not evaluate the degree elevated empowerment that is attained but that targets only distress-related parameters of change might miss a very basic point. Actually, therapeutic intervention—whether conducted online or offline—may be combined with client’s participation in a relevant online support group, thus blending specific treatment and nonspecific, empowering interventions. Such dual approach was offered in several Internet-delivered therapies, including web therapy combined with minimal e-mail contact and a support forum in treating social phobia (Carlbring, Furmark, Steczkó, Ekselius, & Andersson, 2006), web therapy in treating panic disorder and use of a support forum (Carlbring et al., 2005), web therapy in treating weight loss in combination of a support forum (Tate, Wing, & Winett, 2001; Womble et al., 2004), web therapy in treating weight loss in combination of support by an e-mail list (Harvey-Berino, Pintauro, Buzzell, & Gold, 2004), web therapy in treating eating disorders in combination with a support forum (Zabinski, Wilfley, Calfas, Winzelberg, & Taylor, 2004), and group therapy in treating body image via chat room in combination with a support forum (Gollings & Paxton, 2006). It seems that such “hybrid” approach may simultaneously reach specific therapeutic changes and more general, nonspecific empowerment and well-being improvement.

In our view, consequently, the effectiveness of online support groups is difficult to assess not only for methodological reasons (Davison et al., 2000) but also for its different focus of desired measurement. Indeed, we have shown that some studies have shown poor (or limited) effectiveness of such support groups, whether these investigations were comprehensive reviews, such as conducted by Eysenbach et al. (2004), or more specific research, such as evaluations of STARBRIGHT by Hazzard, Celano, Collins, and Markov (2002) and by Holden, Bearison, Rode, Rosenberg, and Fishman (1999). On the other hand, numerous studies have showed how the dynamic processes that occur in online support groups create changes in participants that have to do with a sense of personal empowerment, thereby substantiating our contention. As recently summarized by Tanis (2007), it seems that there are two basic reasons why online support groups succeed: first, they have a direct effect on well-being and personal empowerment; second, they have an indirect effect in serving as a sort of buffer against the negative effects of distressful conditions. In exploiting inherent needs, expectations, and habits, online support groups activate—and actually foster—inner dynamic personality drives that elevate the participants’ sense of power and control and combat feelings of powerlessness typical of people like them in distress.

References


