

## Commentary

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## **Cancer-related electronic support groups as navigation-aids: Overcoming geographic barriers**

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### **ABSTRACT**

Cancer-related electronic support groups (ESGs) may be regarded as a complement to face-to-face groups when the latter are available, and as an alternative when they are not. Advantages over face-to-face groups include an absence of barriers imposed by geographic location, opportunities for anonymity that permit sensitive issues to be discussed, and opportunities to find peers online. ESGs can be especially valuable as navigation aids for those trying to find a way through the healthcare system and as a guide to the cancer journey. Outcome indicators that could be used to evaluate the quality of ESGs as navigation aids need to be developed and tested. Conceptual models for the navigator role, such as the Facilitating Navigator Model, are appropriate for ESGs designed specifically for research purposes. A Shared or Tacit Model may be more appropriate for unmoderated ESGs. Both conceptual models raise issues in Internet research ethics that need to be addressed.

Key Words: Electronic support groups, cancer, mailing lists, navigation aids, Internet research ethics

### **INTRODUCTION**

#### **Electronic support groups**

There is increasing interest in evaluating the impact of Internet-based technologies on cancer outcomes. For example, in a recent review, Eysenbach<sup>1</sup> distinguished four areas of Internet use: communication (electronic mail), community (virtual support groups), content (Web-based health information), and commerce. Of particular interest are electronic support groups (ESGs) in general, particularly mailing lists. ESGs may be the Internet application area with the greatest effect on people with cancer.<sup>1</sup>

ESGs may be regarded as a complement or supplement to face-to-face support groups, or as an alternative. They have several advantages over face-to-face groups such as:

- absence of geographic and transportation barriers;
- opportunities to discuss stigmatizing, embarrassing, or sensitive issues in anonymity;
- an environment that encourages self-disclosure, honesty, and intimacy; and
- opportunities, even for those who have rare diseases, to find peers online.<sup>1</sup>

Some disadvantages include:

- a large volume of mail with a considerable amount of unwanted communication;
- negative emotions (known as "flaming"); and
- a lack of physical contact and proximity.<sup>1</sup>

And, as with Web content, there are concerns about inaccurate information and information that is not based on evidence, (in exchanges about alternative treatments, for example).

Winzelberg et al.<sup>2</sup> have summarized some advantages and disadvantages of ESGs for breast cancer patients. Advantages include flexibility in the modality of delivery (e.g., via mailing lists, chat rooms, etc.), the variety of facilitation options, and the need for fewer resources compared with face-to-face groups. Disadvantages include the need for computer and Internet access and the need to know the language used in the ESG. These authors concluded that ESGs offer many advantages, but cautioned that they present some ethical issues that need to be addressed.<sup>2</sup> The Discussion section that follows includes examples of these issues.

An important issue is whether or support groups of any kind might yield survival benefits in addition to the benefits summarized above. The literature on evaluations of community-based cancer support groups indicates that it is more reasonable to expect an impact of such interventions on psychosocial functioning and/or health-related quality of life than on survival.<sup>3</sup> It also seems reasonable to have similar expectations for ESGs.

### **The 'Internet paradox' controversy**

It is possible that some participants in ESGs could become overly reliant on their Internet-based relationships, resulting in increased social isolation and reduced well-being.<sup>1,2</sup> Eysenbach<sup>1</sup> reviewed this "Internet paradox" controversy and concluded that longitudinal studies or randomized trials are needed to

investigate this issue further. In such studies, efforts should be made to control for sources of selection bias (such as the possibility that depressed persons turn primarily to ESGs for support, while staying away from face-to-face groups).

A recent example of a well-designed study is the randomized controlled trial (RCT) reported by Winzelberg et al.<sup>2</sup> In this trial, a breast cancer ESG was found to be an effective intervention for reducing participants' scores on depression, perceived stress, and cancer-related trauma measures. The effect size of the intervention was in the moderate range.

### **ESGs as navigation aids**

If one accepts the notion that most of those who participate in ESGs may benefit enormously from these interactions, then, how can the quality of ESGs be assessed? I have argued<sup>3</sup> that ESGs can be especially valuable as navigation aids for those trying to find their way through the healthcare system. It has been suggested by Farber et al.<sup>4</sup> that navigation of the healthcare system can be regarded as having four major components: coordination of care, education/information, decision-making and self-care. These authors have also proposed three types of outcome data as appropriate for an evaluation of the navigator role: workload indicators, indicators of patient/client satisfaction, and indicators of more systemic evaluation issues.<sup>4</sup> It should be feasible to develop indicators such as these that are suitable for use in the evaluation of ESGs.<sup>3</sup> Because subscriptions to ESGs are usually free, the cost-effectiveness of such ESGs as navigation aids is determined primarily by their effectiveness in this role.

Of course, the needs of those dealing with breast cancer, for example, depend on each person's particular situation or context:

- pre-diagnosis but high-risk;
- tentative diagnosis not yet confirmed;
- postdiagnosis but with therapeutic decisions yet to be made;
- postdiagnosis and postinitial treatment, but still recurrence free; and
- postrecurrence with metastases; etc.

So, the quality of navigation assistance provided for the various phases along the trajectory of the cancer journey also needs to be taken into account in efforts to evaluate the navigator role of ESGs.

### **Models of navigation**

On the basis of their study, which addressed the status of the navigator role for meeting the needs of women with breast cancer in Canada, Farber et al.<sup>4</sup> identified three conceptual models. The first was the Active Coordination Model, in which a navigator is actively involved in helping affected individuals. The second was the Facilitating Navigator Model, in which the navigator provides

information, support, and encouragement. The third was the Shared or Tacit Model, in which several people provide navigation, either tacitly, or by design.<sup>4</sup> This third model is of particular interest in relation to ESGs that rely mainly on navigation provided by participating peers rather than on navigation provided by participating health professionals.<sup>3</sup> These models will provide the conceptual framework for the remainder of this commentary. They can also be helpful to those who are interested in ESGs and their possible impacts on health outcomes, and can be viewed as a case study in the emerging field of integrative cancer research.

## **DISCUSSION**

### **An example of a Facilitating Navigator Model**

The ESG used as the intervention in the RCT carried out by Winzelberg et al.<sup>2</sup> was developed for the purposes of their research. It was a semistructured ESG moderated by a healthcare professional and delivered in an asynchronous newsgroup format. It is noteworthy that the involvement of a health professional as the moderator (or facilitator, or navigator), and some aspects of the format and the eligibility of participants, could be regarded as features of this study that were imposed by the RCT design.<sup>3</sup> In effect, the navigation model used by these investigators was a Facilitating Navigator Model, in which the major role of the navigator was to provide information, support and encouragement.

As noted above, Winzelberg et al.<sup>2</sup> identified some ESG-related ethical issues associated with the ESG model they had adopted. One ethical issue was how to inform participants about the limitations of the moderator's role. Participants were told, prior to joining the study, that the intervention was a psychoeducational support group. It was not meant to provide a form of psychotherapy, nor was it intended to be an alternative to psychotherapy. Members of this ESG could offer each other advice, but the group moderator (navigator) refrained from doing so.

A second ethical issue was the privacy of the participants.<sup>2</sup> The Web site used in the intervention was password-protected. Participants could read personal stories from survivors and share their own experiences. They could also keep a Web-based personal journal, but the personal journals were closed to review by other members of the ESG.

In this intervention,<sup>2</sup> participants were told not to disclose any information that they learned about group members to others, and to refrain from allowing family members or friends access to the Web site. Participants were also warned that, because no Internet-connected system can be completely secure from attack by skilled hackers, there are limits to the confidentiality of any Web-based intervention.

But, as the authors<sup>2</sup> pointed out, the best protection for the privacy of participants in ESGs is that provided by security practices of the participants themselves. For example, they should avoid providing access to the intervention Web site to anyone who is not participating in the research. Also, participants in ESGs should be reminded regularly of the limits of confidentiality of Internet-based interventions, and they should treat their postings as potentially public documents.

Whether or not the ESG was originally set up for research purposes, the approval of an Institutional Review Board (IRB) or Research Ethics Board (REB) should be sought before proceeding with research involving a health-related ESG.

### **An example of a Shared or Tacit Model**

I have suggested previously<sup>3</sup> that the Breast-Cancer mailing list (BCML) provides a good example of a Shared or Tacit Model of navigation. The BCML, established in early 1994, is an unmoderated English-speaking ESG. It is based at Memorial University of Newfoundland in St. John's, and had about 320 subscribers on January 1, 2004. Although the server that supports the BCML is located in Canada, the majority of members are located in the United States.

A Web site for the BCML is available.<sup>5</sup> Via this Web site, it is possible to join or leave the mailing list and open access is provided to archives of messages posted to the list. Messages stored in such open archives clearly should be regarded as publicly accessible documents (even if those who posted them have not designated them as belonging in the public domain). However, some privacy is provided by the likelihood that this small, but active, segment of cyberspace may be of limited interest to anyone other than those directly involved with breast cancer. Also, even though the archives can be searched internally using key words, they are not accessible to popular search engines, such as Google.<sup>6</sup>

The volume of mail and the number of off-topic messages, while facilitating some privacy, are sometimes a cause for complaints. On the other hand, the number of BCML members and the number who actively participate are sufficient to ensure that new subscribers will be able to identify appropriate "tacit peer-navigators". Such peers can help new members find their way through the various phases of the cancer journey. Initial exchanges of information and provisions of support occur on the list, but may subsequently move off the list. Exchanges of private email messages appear to happen frequently. And, for those list members who discover that they live close to each other, face-to-face meetings can be arranged. Interactions of this kind can enhance both social support and privacy.

### **Some issues in Internet research ethics**

The existence of open archives of messages posted to ESGs (such as the BCML) poses some novel challenges in research ethics for ESG researchers and scholars. The BCML was not established as part of a research protocol. The participants have not given their informed consent to serve as participants in a research program. Yet, the BCML and its open archives can serve as a rich source of qualitative data about, for example, the needs, values, and preferences of healthcare consumers.<sup>7</sup>

From a biomedical perspective, participants in existing ESGs that were not set up for research purposes should still be regarded primarily as research subjects, and the proposed research protocol should be reviewed by an IRB or REB. For example, the members of an IRB, not the researchers themselves, should make the decision about the extent to which an open ESG, such as the BCML, should be regarded as a semiprivate (rather than public).

From this biomedical perspective, well-known principles of research ethics, such as those outlined in the Belmont Report,<sup>8</sup> may provide appropriate guidance. Issues that merit attention include:

- respect for persons;
- informed consent;
- privacy and confidentiality;
- potential benefits vs. potential harms; and
- justice and fairness in the distribution of such benefits and harms.

Although guidelines and proposals for Internet research ethics are usually based on those designed for human subjects research, researchers in the humanities may have quite different perspectives. They may be aware of instances in which human subjects guidelines do not apply to complex Internet material. Some examples are provided in contributions to a panel presentation organized for a conference on Internet research ethics held in December 2001.<sup>9</sup> From this perspective, one can ask in relation to participants in an ESG: "Are participants in this environment best understood as subjects (in the context of human subjects research in medicine and social sciences) or as authors whose texts/artifacts are intended as public?"<sup>10</sup>

An in-depth consideration of this question is beyond the scope of this commentary. However, one answer is that participants in ESGs should sometimes be regarded as research subjects, sometimes as authors, and sometimes as members of a community. Perhaps most often, they should be regarded as some combination of all three, depending on the context and the preferences of the individual ESG participants. Above all, the Belmont principle<sup>8</sup> of respect for persons should prevail.

## **CONCLUSION**

ESGs are an Internet application area of great interest, especially from the perspective of integrative cancer research. Evidence has accumulated about their many advantages, as well as their disadvantages. They can be regarded as navigation aids that can help participants find an appropriate path through the healthcare system and serve as a guide to the cancer journey. The quality of ESGs as navigation aids should be evaluated. The Facilitating Navigator Model appears to be an appropriate conceptual model for the navigator role for professionally moderated ESGs that have been set up specifically for research purposes. In contrast, a Shared or Tacit Model appears to be a more appropriate model for unmoderated ESGs. Both models raise issues in Internet research ethics that must be addressed.

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