

Commentary

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Evaluation of support groups for women with breast cancer: importance of the navigator role

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Abstract

Background: At least some forms of breast cancer are increasingly being viewed as a chronic illness, where an emphasis is placed on meeting the various ongoing needs of people living with cancer, their families and other members of their social support networks. This commentary outlines some approaches to the evaluation of cancer-related support groups, with a particular emphasis on those designed to provide long-distance support, via the internet, for women with breast cancer.

Discussion: The literature on evaluations of community-based cancer support groups indicates that they offer a number of benefits, and 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. The literature on both face-to-face and online social support groups suggests that they offer many advantages, although evaluation of the latter delivery mechanism presents some ethical issues that need to be addressed. Many popular online support groups are peer-moderated, rather than professionally-moderated. In an evaluation of online support groups, different models of the role of the "navigator" need to be taken into account. Some conceptual models are outlined for the evaluation of the "navigator role" in meeting the informational, decisional and educational needs of women with breast cancer. The Breast-Cancer Mailing List, an example of an unmoderated internet-based peer-support group, is considered within the context of a Shared or Tacit Model of the navigator role.

Conclusion: Application of the concept of a "navigator role" to support groups in general, and to unmoderated online ones in particular, has received little or no attention in the research literature. The navigator role should be taken into account in research on this increasingly important aspect of cancer communication.

Background

Cancer communication can be regarded as an attribute of good-quality care [1]. And, a critically-important arena of cancer outcomes research is quality of care, including ways to disseminate the results of relevant outcomes research to users [1]. Increasingly, care is moving from hos-

pitals to ambulatory care settings, to community facilities, and the home [2]. Such shifts in the locus of care can have major implications for those for whom access to institutional settings may be restricted, for reasons such as geographical location or socioeconomic status. The increasing private and public availability of internet-con-

nected computers has created opportunities for overcoming some of these barriers to communication in general, and to the dissemination of relevant outcomes research in particular. For example, Industry Canada has supported programs designed to bring publicly available broadband access to Canadian communities, with priority given to First Nations, northern, remote and rural communities [3]. These communities are currently either unserved or underserved.

At least some forms of breast cancer are increasingly being viewed as a chronic illness, where an emphasis is placed on meeting the various ongoing needs of people living with cancer, their families and other members of their social support networks [4]. Models of care have evolved which place greater emphasis on meeting the needs of a particular situation, rather than on the roles of particular health professionals [4]. Examples of particular situations may be selected from a very wide range of cancer control activities, including ones designed to provide information and support to those living with cancer, or to those who are at an increased risk of cancer.

An aspect of good-quality care that has received increasing recognition is health-related quality of life (HQOL). HQOL is a dynamic phenomenon, which can change in response not only to various manifestations of a disease, but also to a variety of external influences [2]. Like other aspects of cancer outcomes research, research on HQOL needs to involve the perspectives of the recipients of care, if only because of the importance of focusing on HQOL outcomes not only at the level of populations, but also at the level of individuals [2,5].

Although reliable and valid indicators of HQOL are a crucial aspect of cancer outcome studies [2], appropriate attention also needs to be paid to the transfer of research findings into practical applications [5]. A conceptual framework for cancer control research [6], developed in Canada, was designed to foster a wide range of cancer control research activities. These activities include research related to the development and implementation of interventions and research related to the development and evaluation of programs designed to deliver effective interventions in a well-organized manner. The evaluation of such interventions and programs is an important aspect of outcomes research on quality of care.

A variety of psychosocial interventions have been designed to enhance the HQOL of cancer patients [7-9]. In this commentary, the focus will be on the evaluation of cancer-oriented support groups, including both face-to-face groups and those designed to provide long-distance support via the internet. A particular emphasis will be placed on evaluation of the "navigator role" in meeting

the informational, decisional and educational needs of women with breast cancer [4].

Navigation of the care system can be regarded as having four major components: coordination of care, education/information, decision-making and self-care [4]. And, of course, the needs of women will be dependent on their current situation in relation to breast cancer (e.g. pre-diagnosis but high-risk, post-diagnosis but recurrence-free, post-recurrence with metastases, etc.). So, assistance provided in relation to navigation of the various phases along the trajectory of the "cancer journey" also needs to be taken into account in efforts to evaluate the "navigator role".

Discussion

Support groups for women with breast cancer

To cope with their illness, many women participate in breast cancer support groups.

In a review published in 2000, Davison et al. [10] assessed participation in a wide variety of disease-related internet-based support groups. They reported that support groups for breast cancer were highly-ranked, as measured by prevalence-adjusted indices of overall online support activity, in comparison with other disease-related and cancer-related on-line support groups that were evaluated. They also reported similar results for disease-related and cancer-related face-to-face support groups in four major metropolitan areas in the USA [10].

A research question is: do internet-based and face-to-face support groups involve similar probable benefits and possible harms?

Usually, the support groups that have been studied have been face-to-face ones. One example is a study of 24 women in four community breast cancer self-help groups in Ontario, Canada [11]. Reported benefits of group involvement included both emotional support benefits and informational and practical support benefits. Emotional support benefits included connecting with other breast cancer survivors, feeling understood, providing hope, and sharing experiences, including healing laughter. Informational and practical support benefits included sharing of important information and "learning how to get what you want". Issues identified as problematic included how to deal with deaths of group members and how to balance the group's primary purpose of providing mutual support with secondary goals of dealing with group business and engaging in meaningful advocacy [11]. In a recent succinct review of the literature [12], it's noted that although there is empiric evidence that community-based support groups are beneficial, not all studies have reported positive outcomes.

An important issue is whether or not support groups of any kind might yield benefits not only for HQOL, but also for survival. Spiegel, in an editorial published in 2001 [13], has concluded that the literature is divided, and that "group therapy for patients with cancer can be prescribed for its psychological benefit, if not necessarily for any prolongation of survival". Goodwin et al. [9] reviewed the results of trials of various psychosocial interventions, ranging from support groups to individual or couple counseling, and concluded that, rather than an effect on survival, it is more reasonable to expect an impact of such interventions on psychosocial functioning and/or HQOL.

In summary, research on face-to-face support groups has provided evidence that they usually, but not always, have beneficial impact on HQOL. This research provides support for the view that self-help groups, whether online or face-to-face, are most likely to be beneficial when they are focused on their primary purpose of providing mutual support about navigating various phases of cancer.

Evaluation of web-based breast cancer support groups

Only a few studies of web-based breast cancer support groups have been reported [12,14–19]. One of these studies, by Klemm et al. [17], involved line-by-line analysis of postings on prostate, breast, and mixed internet-based cancer support groups. Four categories of responses (information giving/seeking, encouragement/support, personal opinion, and personal experience) accounted for approximately 80% of responses across the groups. Personal experience took priority in the breast group, while information giving/seeking was ranked first in the prostate group. Women were more than twice as likely to give encouragement and support, and men were more than twice as likely to give information [17].

Some of the advantages and disadvantages of online support groups for breast cancer patients have recently been summarised [12]. Advantages include flexibility in the modality of delivery (e.g. via discussion groups, chat rooms, etc.), a variety of facilitation options (in comparison with face-to-face groups), and the comparatively fewer resources required. Disadvantages include the need to be able to access and use computers and the internet and to be comfortable in the language which the online group is using. There is also a possibility that participants could become over-reliant on their internet-based relationships, resulting in increased social isolation.

Winzelberg et al. [12] have also reported the results of a randomized controlled trial (RCT). This trial is of particular interest, because it provides a good example of issues that are encountered when a RCT, a "gold standard" of experimental design, is used for the evaluation of online support groups. In the trial, 72 women with primary

breast carcinoma were randomly assigned to a 12-week, web-based, social support group. The support group was semistructured, moderated by a health care 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. This web-based program was found to be effective in reducing participants' scores on depression, perceived stress, and cancer-related trauma measures. The effect size of the intervention was in the moderate range.

These authors [12] concluded that web-based social support groups offer many advantages, but cautioned that this delivery mechanism presents some ethical issues that need to be addressed. One ethical issue they identified: how do the participants understand the limits of the moderator's role? To deal with this issue, participants were told, before joining the study, that the intervention was a psychoeducational support group, and was not meant to serve as a form of psychotherapy, nor as an alternative to psychotherapy. Group members offered each other advice, but the group moderator refrained from doing so.

A second ethical issue considered by these authors [12] was the privacy of the participants. The website used in their study was password-protected. Participants were able to read personal stories from survivors, share their own experiences, and keep a web-based personal journal. However, the personal journal was closed to review by other group members, and, in this intervention, participants were instructed not to disclose any information that they learned about group members to others, and not to allow family members or friends to access the website. Participants were also warned that there are limits to the confidentiality of any web-based intervention, because no internet-connected system can be completely secure from attack by skilled "hackers". But, the authors [12] pointed out that the most likely threat to the privacy of group participants is their own security practices, such as allowing non-group members to view the website. Participants in such groups should be reminded regularly of the limits of confidentiality of internet-based interventions, and should treat their postings as potentially public documents.

Because there is some ambiguity about the legal responsibilities of moderators of online support groups, these authors [12] also made a conservative decision to restrict eligibility to participants who resided in the same state (California) in which the moderators were licensed to practice psychology.

Although in this RCT [12], the moderator was a health professional (a psychologist), many popular online support groups are peer-moderated, rather than professionally-moderated. In an evaluation of online support groups, different models of the role of the "navigator" need to be taken into account.

Conceptual models for the role of the navigator

Farber et al. [4], in their review of the literature, found that numerous terms were used to describe the role of various kinds of navigators in the health care system, such as case manager, clinical coordinator, support nurse, etc. The term "patient navigator" was rarely used. In the first of two examples that were identified [4], the patient navigator acted as an advocate for patients with abnormal breast cancer screening findings in underserved areas of the Bronx, New York [20]. In the second example, the patient navigator ("the Native sister") accompanied Native American women to follow-up appointments and provided emotional support and advocacy [21]. A subsequent publication by the latter group [22] describes the Native American Cancer Survivors' Support Network, initiated in 1999. This innovative public health program is designed to improve survival from cancer and the quality of life after a cancer diagnosis for American Indians, Alaska Natives, and Canadian Aboriginal patients and their loved ones [22].

Farber et al. [4] also performed an environmental scan of existing navigator roles in Canada. Key informants who might have information about the navigator role were identified, and 74/186 of these key informants were interviewed. On the basis of this study of the status of the navigator role for meeting the needs of women with breast cancer in Canada, three conceptual models were identified [4]. In the Active Coordination Model, the navigator is actively involved in helping affected individuals to navigate a way through the care system. In the Facilitating Navigator Model, the navigator provides information, support and encouragement. The Shared or Tacit Model involves several people providing navigation, either tacitly, or by design [4].

Approximately 38% of the key informants were located in rural or semi-rural communities [4]. The only difference noted was that navigators in smaller communities might be more involved in transportation arrangements for patients (e.g. if the needed facilities weren't located within the community). Otherwise, there was a remarkable similarity in navigator roles.

Key informants were also asked what they believed, on the basis of their knowledge and experience, should be the key evaluation factors for the navigator role [4]. Generally, three types of outcome data were identified: workload in-

dicators (such as number of calls received), indicators of patient/client satisfaction (such as meeting patient/client expectations) and indicators of more systemic evaluation issues (such as measures of cost-effectiveness).

Might these same conceptual models for the navigator role, and these same approaches to their evaluation, also be applied to internet-based support groups? For example, perhaps the role of the moderator in the web-based support program described by Winzelberg et al. [12] could be regarded as an online version of the Facilitating Navigator Model of Farber et al. [4]?

In the next section, another example of an internet-based support group (the Breast-Cancer Mailing List) will be considered briefly. It provides an example of the Shared or Tacit Model of Farber et al. [4], a model quite different from their Facilitating Navigator Model.

The Breast-Cancer Mailing List (BCML)

The BCML was established in early 1994, and has operated continuously since that time [23,14]. It's an unmoderated English-speaking online (via email) discussion group, based at Memorial University of Newfoundland in St. Johns, Newfoundland, Canada. The BCML had about 370 members on March 1, 2003 [24]. Although it is based in Canada, the majority of members are from the USA, with the remainder from Canada and other countries around the world [23]. The volume of mail, often nearing a hundred messages a day, is sometimes a cause for complaint – at least until new members learn ways of prioritising their email [23]. On the other hand, the number of members, and their level of activity on the BCML, is sufficient to ensure that new subscribers are likely to be able to find other people who are, or have recently been, in a very similar situation. Such people can provide well-informed peer support for new subscribers. In addition, because different members of the BCML have already experienced different phases along the trajectory of the "cancer journey", they can serve as "tacit peer-navigators", and help new members to find their way through the various phases of the journey.

Also, a website for the BCML is available [23]. It provides access to convenient ways to join or leave the mailing list. It also provides access to archives of messages posted to the list. Statistical information about the frequency and types of visits to these archives have not been provided via the website, but it seems likely that present and former list members (and perhaps others) visit and use them frequently. So, messages found in such archives clearly should be regarded as public documents, even though this particular small segment of cyberspace is likely to be of much interest only to those directly involved in some way with breast cancer.

The use of online support groups such as the BCML (and their archives) for research purposes raises ethical issues of privacy and informed consent that need to be considered carefully [25]. The members of disease-related mailing lists of this kind can freely choose whether or not to participate in an online support group where their postings are potentially public documents. But, new subscribers may join and participate in a mailing list before they become fully informed about its various features. And, their particular personal situations may involve a vulnerability that is much greater than that of participants in online discussion groups that are not health-related. The more vulnerable the participants, the greater the need for careful attention to privacy and confidentiality. For example, the archives of a mailing list for patients with metastatic breast cancer are password-protected [26].

For an unmoderated mailing list like the BCML, concerns about the limits of the moderator's role [12] are replaced by different issues. One example of such an issue: which members of an unmoderated list tacitly play "peer-navigator" roles (as in the Shared or Tacit Model of Farber et al. [4])? A working hypothesis can be based on this particular conceptual model. The hypothesis is that good-quality unmoderated online support groups can be characterized as ones where respected long-time ("veteran") members serve as "tacit peer-navigators" and become quite skilled in this role. An example is provided by Musa Mayer, a "veteran" of the BCML [14] and a frequent contributor. She is the author of three books about breast cancer, and a respected breast cancer activist [27]. Her perspectives have been influenced by her experiences with counselling, with her own breast cancer, and with the BCML.

To test this hypothesis, it should be feasible to collect examples of the three types of outcome data that were identified by Farber et al. [4] as appropriate for an evaluation of the navigator role. An example of a workload indicator might be the number of navigation-oriented messages posted (e.g. per week) by list members tentatively identified as "tacit peer-navigators". An indicator of patient/client satisfaction might be the number of spontaneously-posted messages that express satisfaction with the mailing list in general, and with the contributions of "tacit peer-navigators" in particular. An example of an unsolicited quote from a posting to the BCML [23]:

"This group is at its best when they can help someone going through a rough time. You see, we have all been there and understand the fears, nervousness and what ever else plagues us at times like these".

It might also be feasible to develop indicators of more systemic evaluation issues, such as measures of cost-effectiveness. For example, because subscriptions to the BCML are

free, and the "tacit peer-navigators" are volunteers, the navigator role is fulfilled at no extra cost to list members. So, the main systems evaluation issue remains one of assessing the effectiveness of online support groups, in comparison with each other, and with more conventional face-to-face support groups. It seems reasonable to assume that online support groups can be regarded as a complement to face-to-face support groups (when the latter are available) and as an alternative when they are not. Whether or not this assumption is correct, another important systems evaluation issue is: how best to evaluate the effectiveness of the navigator role? It seems likely that the greater the effectiveness of the navigator role, the greater the cost-effectiveness of the support group, whether or not it's online. From this perspective, systemic evaluation outcome variables, and especially ones focused on the navigator role, may be the most crucial ones for which appropriate measures need to be designed and implemented.

Conclusion

Application of the concept of a "navigator role" to support groups in general, and to unmoderated online ones like the BCML in particular, has received little or no attention in the research literature. The navigator role should be taken into account in outcome-oriented research on this increasingly important aspect of cancer communication.

List of abbreviations

BCML: Breast-Cancer Mailing List

HQOL: Health-related quality of life

RCT: Randomized controlled trial

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