

Not alone: peer support through audio teleconferencing for rural women with breast cancer



From the front lines

Aux premières lignes

Vernon R. Curran, MEd; Jon G. Church, PhD

The impact of breast cancer on the emotional and social health of women and their families is an important issue. A diagnosis of cancer marks the start of a stressful illness with a long period of medical treatments and side effects, prognostic uncertainty, disfigurement and general disruption of life. Many survivors and health care professionals have identified the need for continuing adequate psychosocial support for long-term adaptation to breast cancer; such support may even affect survival.¹ Nevertheless, only between 1% and 10% of patients with breast cancer participate in group interventions,² and evidence suggests that medical, practical and stylistic barriers may account for this underuse.³ Stylistic barriers consist of attitudes of potential members that are inconsistent with the group's format (for example, individuals may be too shy to join a formal group) or subject matters that render the meetings boring. For rural communities, practical hurdles often predominate. These include lack of health services, small population and geographic isolation. For many, this leads to a perception of "being alone" on the long road to recovery.

Communications and computer-based technologies can overcome some of the obstacles that reduce the use by breast cancer survivors of face-to-face peer-group interventions.^{2,4-11} One example of the application of computer technology in bridging distance is the development of the Internet BREAST-CANCER List-Serv and virtual support group (based at Memorial University of Newfoundland). Audio teleconferencing technology also offers a powerful means for linking many people through real-time discussion. It can facilitate support for geographically isolated individuals and situations, including breast cancer survivors.

A significant rural population scattered along a vast and rugged coastline characterizes Newfoundland and Labrador's population of over 500 000. With up to 200 new cases of breast cancer diagnosed each year, this province is an excellent example of how geographic barriers influence the desire for and availability of support programs. However, the province is also home to the most extensive telemedicine and audio teleconferencing system in Canada, operated by the Telemedicine Centre, Faculty of Medicine, Memorial University of Newfoundland. The audio teleconferencing network is divided into 11 separate circuits with a total of 217 sites (primarily located in secondary and postsecondary educational institutions, hospitals and medical clinics) in about 150 communities throughout the province (Fig. 1).

In the spring of 1997, with the support of the Newfoundland and Labrador Division of the Canadian Cancer Society, we initiated a pilot project aimed at examining whether we could effectively facilitate a self-help peer support group for rural breast cancer survivors through this audio teleconferencing network.

The teleconferencing self-help support pilot project

We carried out the teleconference support sessions from an audio teleconferencing studio in the Telemedicine Centre's main operation facilities. We offered biweekly sessions on Saturdays beginning in April 1997 and concluding at the end of June 1997. The community-based cancer survivor volunteer network of

Mr. Curran is an Educational Consultant with the Faculty of Medicine, Memorial University of Newfoundland, and Dr. Church is an Associate Professor with the Terry Fox Cancer Research Laboratories, Faculty of Medicine, Memorial University of Newfoundland, St. John's, Nfld.

This article has been peer reviewed.

CMAJ 1998;159:379-81



the Canadian Cancer Society, CanSurmount, promoted the teleconferencing program within their communities. In addition, we distributed posters through nurses involved in the Breast Screening Program for Newfoundland and Labrador and the Newfoundland Cancer Treatment and Research Foundation. Short press releases were also prepared, and local radio and print media across the province played a role in promoting the project. Participation at each session ranged from a high of 48 women in 21 separate communities to a low of 17 participants in 7 communities.

Teleconference sessions began at 11:00 am with a teleconference operator carrying out a general equipment orientation and sign-on of participating sites across the provincial teleconferencing network. The operator then handed the session over to the teleconferencing facilitator (J.G.C.) who usually initiated the sessions by reminding participants of the issue of confidentiality: participants were to identify themselves by community or first name only. The facilitator reviewed his role as a liaison and resource person, stressing that the main goal of the sessions was to have the participants ask for and offer assistance to each other; it was not the facilitator's role to establish the objectives for discussion. Before opening each session to the concerns of the participants, the facilitator took a count of sites and participants and invited participants to

say a few words about who they were and their relation to breast cancer.

The topics of conversation varied widely — breast cancer detection and mammography; breast self-examination; management of hot flashes; lymphedema; diet, exercise and the prevention of recurrences; bone marrow transplantation; coping with chemotherapy; hormone replacement therapy; support from and to extended families and children; aftermath of mastectomy, including esthetics and sexuality; breast reconstruction; pregnancy after breast cancer; bereavement, death and dying — and although the facilitator's investigation and comments on a particular topic from a previous session might prompt initial conversation, most topics were suggested and discussed by the participants themselves. The sessions ran for 70–90 minutes and concluded with thanks and an invitation from a representative of the Canadian Cancer Society to participate in the next session.

After completing the pilot project, we developed a questionnaire to assess participants' satisfaction with the self-help program and the use of audio teleconferencing technology. We distributed this questionnaire to 50 participants through our regional CanSurmount volunteers. The questionnaire, containing open- and closed-ended questions, was divided roughly into 4 parts: participants' age, education, community size and breast cancer experience; their level of satisfaction with the technology, the program format and delivery options, and the presence of certain therapeutic elements common to face-to-face support groups; their opinions regarding time and day of program delivery and design of the sessions and their preferences for the facilitation; and invited comments on participants' perceptions of the advantages and disadvantages of the program and the use of audio teleconferencing for a self-help support network at a distance.

Seventeen respondents returned surveys, for a possible return rate of 34%. It is important to note that this return rate is an estimate: the program coordinators did not keep formal registration or participation records over the 6 sessions. We conducted the program with the understanding that its initial success was dependent on it being anonymous, informal and open-ended. We did not ask nor expect participants to reveal their full names or where they lived.

Of the 17 respondents, 10 (59%) were under the age of 40 years, although breast cancer is most common among women who are over the age of 40.¹² Seven of the respondents (41%) had a high school diploma and 6 (35%) a postsecondary diploma or degree.

The responses also suggested that there was a good mix of newly diagnosed patients and long-term survivors in the program. One-third of the respondents were less than 1 year from their last surgery or treatment, whereas one-quarter were more than 5 years from their last treat-

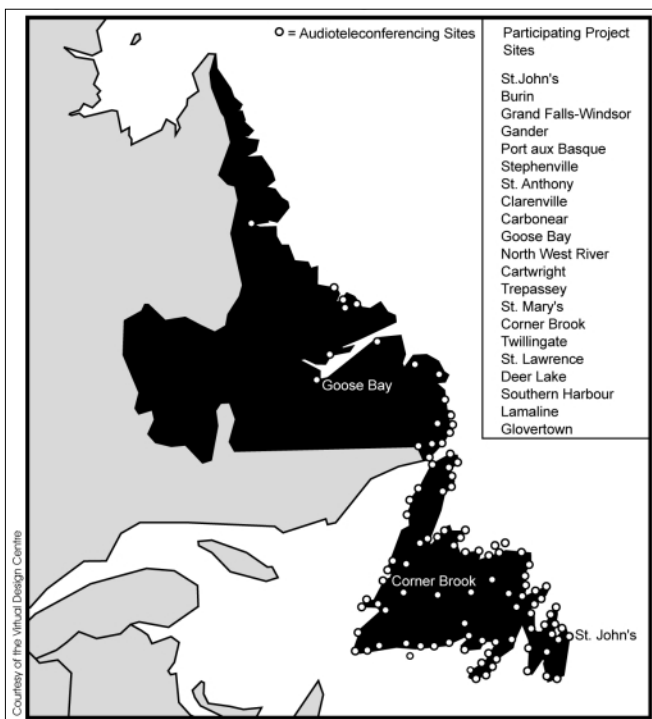


Fig. 1: Audio teleconferencing sites, located in secondary and postsecondary educational institutions, hospitals and medical clinics in about 150 communities throughout Newfoundland and Labrador.



ment. The success of self-help support groups depends on having members in the group who are at different stages of the disease. More recently diagnosed individuals can share anxieties with the longer-term survivors, who in return can offer support and hope. The open-ended comments also suggested that participants had positive opinions of the social support and information shared by longer-term survivors.

Perhaps what is most important is that the respondents' overall perceptions of this self-help support program at a distance were positive. A large majority strongly agreed or agreed that the teleconferencing sessions addressed their need for social support and information on breast cancer. As well, many indicated strong interest in attending future teleconferencing sessions and strongly agreed that it would be important for the teleconferencing sessions to continue. Clearly, respondents were satisfied with the program and the extent to which it met a perceived need for information and support from other survivors. Many respondents commented that the program made them feel "not alone" in their struggle with breast cancer. Others noted that the program offered an opportunity "to share and hear the experiences of others." In addition, several participants stated that the program made them "feel good" and that "it was nice to have a program in rural areas" that provided "emotional support" to breast cancer survivors.

Several responses concerning the audio teleconferencing technology suggest that the participants were satisfied with its use and that the technology itself was not a deterrent or inhibiting factor for this self-help support network. Participants were also questioned on the perceived strength of several therapeutic and curative factors common to face-to-face self-help support groups, including universality, "the realization that others have similar problems," which empowers participants to share their personal experiences and feelings through the knowledge that others will understand them; group cohesion, "the recognition of commonalities," which leads to the formation of strong emotional and personal bonds among participants; and the instillation of hope through the development of positive perceptions of one's self, illness and situation.¹³ The respondents were satisfied with their perception of the presence of these factors.

We also received several comments about the program's disadvantages, including a suggestion that "the sessions were too short to allow everyone to talk." One participant noted that she was "reluctant to speak due to unfamiliarity with the equipment." One woman suggested that the "lack of follow-up support and face-to-face interaction" was a disadvantage.

In the end, however, what is evident is that audio teleconferencing technology *can* satisfy many of the self-help

support needs of rural breast cancer survivors, so much so that the Newfoundland and Labrador Division of the Canadian Cancer Society has continued to support these twice-monthly sessions as a regular part of their patient services and support program through 1997/98. Participating women found the program beneficial in bridging the isolation gap that rural women with breast cancer often experience. By sharing experiences and providing support at a distance, these women were often able to overcome the isolation they experience in their struggle with breast cancer. As many women suggested, the audio teleconferencing program made them feel "not alone" in their struggle to cope and to recover.

This project would not have been possible without the financial support and help of both staff and volunteers of the Newfoundland and Labrador Division of the Canadian Cancer Society.

References

1. Spiegel D, Bloom JR, Kraemer HC, Gottheil E. Effect of psychosocial treatment on survival of patients with breast cancer. *Lancet* 1989;2:888-91.
2. Health Canada. *Investigating psychosocial adjustment in breast cancer: a discussion paper*. Ottawa: Minister of Public Works and Government Services; 1997.
3. Bond GR, Daiter S. Participation in medical self-help groups. In: Lieberman MA, Borman LD, editors. *Self-help groups for coping with crisis: origins, members, processes and impact*. San Francisco: Jossey-Bass; 1979. p. 164-80.
4. Weinberg N, Schmale JD, Uken J, Wessel K. Computer-mediated support groups. *Soc Work Groups* 1995;17(4):43-54.
5. Weinberg N, Schmale J, Uken J, Wessel K. Online help: cancer patients participate in a computer-mediated support group. *Health Soc Work* 1996; 21(1):24-9.
6. Finn J. Computer-based self-help groups: a new resource to supplement support groups. *Soc Work Groups* 1995;18(1):109-17.
7. Finn J, Lavitt M. Computer-based self-help/mutual aid groups for sexual abuse survivors. *Soc Work Groups* 1994;17(1/2):21-46.
8. Evans RL, Jaureguy BM. Phone therapy outreach for the blind elderly. *Gerontologist* 1982;22(1):32-5.
9. Evans RL, Fox HR, Pritzl DO, Halar EH. Group treatment of physically disabled adults by telephone. *Soc Work Health Care* 1984;9(3):77-84.
10. Rounds KA, Galinsky MJ, Stevens LS. Linking people with AIDS in rural communities: the telephone group. *Soc Work* 1991;36(1):13-8.
11. Rosenfield M, Urben L. *Running a telephone cancer support group: evaluation of a short-term project*. London: CancerLink; 1994. p. 1-22.
12. National Cancer Institute of Canada. *Canadian cancer statistics 1997*. Toronto: The Institute; 1997.
13. Weinberg N, Uken JS, Schmale J, Adamek M. Therapeutic factors: their presence in a computer-mediated support group. *Soc Work Groups* 1995; 18(4):57-69.

Reprint requests to: Vernon R. Curran, Faculty of Medicine, Memorial University of Newfoundland, St. John's NF A1B 3V6; fax 709 737-7054; vcurran@morgan.ucs.mun.ca