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"Voices and Faces": A Qualitative Study of Rural Women and a Breast Cancer Self-help Group via an Audio Teleconferencing Network

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ABSTRACT

This project focuses on exploratory research with recent immigrant women in Nova Scotia and their experience with and access to healthcare. This report is based on a pilot exploratory study.

We conducted focus groups with 23 women migrated from 11 countries. Focus groups seem to be an appropriate method for data collection while providing a venue for participant empowerment. The informed participation of immigrant community organizations, participants and family members is key to the success of ethnocultural research. Several other findings emerged: dissatisfaction towards diagnosis and prescription; provider and consumer communication problems; clashes between ethnocultural beliefs and the Western healthcare system; and a link between unemployment or underemployment and physical and emotional health.

This research-based knowledge revealed the need for further research leading to policy changes in healthcare.

1.0 SUMMARY OF THE RESEARCH PROJECT

1.1 GOALS AND OBJECTIVES

The goal of this research was to develop an explanatory model of the use of audio teleconferencing in the provision of social support to survivors of breast cancer among women living in rural Newfoundland. The specific objectives were: 1) to identify the process by which the use of audio teleconferencing provides social support and delineate the therapeutic factors in the process; 2) to identify what support needs these women have; 3) to determine which needs are being met and which are not being met; and, 4) to identify the role that the technology plays in providing the support.

1.2 CURRENT KNOWLEDGE

Women who have been diagnosed with breast cancer have a number of psychosocial needs. These needs have been well documented and vary by age, type of surgery and treatment regime, as well as, where the woman is in the recovery process (Bartmann & Roberto 1996; Bilodeau & Degner 1996; Bunston & Mings 1995; Graydon et al. 1997; Harrison-Woermke & Graydon 1993; Koopman et al. 1998; Lugton 1997; Luker et al. 1995; Nelson 1996; Silliman, Dukes, Sullivan & Kaplan 1998; Trief & Donohue-Smith 1996). Needs identified generally include physical, psychological, and social aspects of care and treatment of the disease including side-effects; treatment options and decision-making; effects on others, including risk to female family members; sharing the illness experience and connecting with other breast cancer survivors; and gaining a sense of control (Luker et al 1995; Northouse & Northouse 1987). Research suggests that face-to-face self-help support groups, the most common form of delivering formal social support, may be an effective means of helping women meet these needs (Alliance of Breast Cancer Survivors Support Group, (n.d.); Cope 1995; Ferrell, Grant, Funk, Otis-Green & Garcia 1997; 1998; Gray, Fitch, Davis & Phillips 1997; McLean 1995; Pilisuk, Wentzel, Barry & Tennant 1997; Samarel, Fawcett & Tulman 1997; Sparks 1988). However, rural women are at a disadvantage when it comes to having these needs met through formal social support programs because of their geographical isolation and difficulties travelling to larger centres where the groups are more likely to be held. For rural women to receive support creative strategies need to be put in place to overcome some of these barriers and facilitate their participation in support programmes.

One means of offering social support to women with breast cancer who are disadvantaged by geographical isolation is the Internet. Research with survivors of breast cancer who have used this medium for support suggests that the Internet does help meet a number of their needs (Marron 1999; Oster 1998; Sharf 1997; Weinberg, Schmale, Uken & Wessel 1996). Positive results with Internet support have also been reported in meeting the needs of individuals diagnosed with other types of cancer (Fernsler & Manchester 1997; Klemn, Reppert & Visich 1998) or other problems (Finn & Lavitt 1994; Fogel 1998). Teleconferencing is another mechanism for providing support for women with breast cancer and, like the Internet, has the advantage of connecting women who are scattered over a wide geographical distance. Some research on teleconference or telephone support has been done with cancer survivors (George 1998), while other research has examined telephone group support as perceived by practitioners (Galinsky, Schopler & Abell 1997) or for members of groups such as homebound people with multiple sclerosis, end stage Aids, or HIV-infected children and their families (Rittner & Hammons 1992; Rounds, Galinsky & Stevens

1991; Stein, Rothman & Nakanishi 1993; Weiner, Spencer, Davidson & Fair 1993). This research suggests that the benefits derived from teleconferencing support are: meeting informational needs in a direct and timely manner, flexibility in getting together, intimacy and privacy for those stigmatized, and irrelevancy of noticeable differences (Schopler, Abell & Galinsky 1998). Negative factors associated with telephone support groups were attributed to technological problems, inability to pick up on non-verbal cues, and concern about confidentiality. All of these projects connected individuals in their homes with facilitators through the use of telephones. There was no research located which examined the social support set-up described in the present research, that is, small groups of women gathered at a teleconference site who were joined into a larger system that operates over a diverse geographical region. This set-up combines some of the features of face-to-face support with teleconferencing support.

Despite the substantial amount of research on social support, including social support for women with breast cancer, the process by which women receive this support is not well understood or documented. Most of the research in the area has dealt with the type of support women would like to have, their support networks, or evaluation of the types of support received. Much of this research has been quantitative focussing on amount of support received and degree of satisfaction experienced. Swanson and Chapman (1994) criticise the use of purely quantitative research which employs only outcome measures to do evaluation research, because they contend that we miss the other things that occur within a program and the process by which it works. The importance of breast cancer survivor's perceptions of how support in groups occurs and under what conditions has not been explored to any great extent. As a consequence while we have a great deal of descriptive research on aspects of social support, there is less of an understanding of the process. The present research aims to contribute in this area. It builds on previous work by two of the researchers who examined the level of satisfaction in a quantitative study of this program. Their study suggests that rural women with breast cancer were satisfied with audio teleconferencing as a means of social support (Curran & Church 1998, 1999). The present research also contributes to an understanding of how gender may be an important contextual factor in the use of technology especially as it relates to social support (Klemm, Hurst, Dearholt & Trone 1999).

1.3 METHODOLOGY

The study was conducted using grounded theory (Glaser 1978; Glaser & Strauss 1967). In keeping with this methodology women who had attended the audio teleconferencing sessions over the past two years were recruited to take part in the study. Grounded theory is concerned with eliciting from individuals who have experienced a particular event how they define these events and how they act in accordance with what they believed is occurring (Chenitz & Swanson 1986; Morse & Field 1995). Participation in the research was voluntary. All women who had taken part in the social support program were asked to contact one of the members of the research committee if they were willing to take part in an interview to describe how this means of support was helpful to them. The proposal for the study was granted ethical approval from the Human Investigation Committee, Faculty of Medicine, Memorial University of Newfoundland.

The audio teleconferencing network used in the provision of the breast cancer support network reported in this study was that of the Telemedicine Centre, Memorial University of Newfoundland. The network is distinguished by dedicated and dial-up circuits, and a telecommunications bridge. Dedicated circuits are divided into network divisions which may be connected individually or collectively to link together communities from across the province of Newfoundland and Labrador. Dial-up sites may call the Telemedicine Centre bridge to be connected with a dedicated network division. The advantages of a bridge mean that a user who does not have access to regular teleconference sites can access a teleconference from a regular telephone located at their office or home. Over 200 sites in approximately 150 communities form the audio teleconferencing network of the Telemedicine Centre. Audio teleconferencing sites where the woman went to take part in the sessions are located in post-secondary and secondary schools, hospitals, libraries, and community centers across the island of Newfoundland and the coast and interior areas of Labrador. The network is based on the utilization of the current telecommunication system of the provincial telephone service provider.

Data were collected through interactive, unstructured, conversational interviews followed by some semi-structured questions. This format was used to allow the woman first to discuss what she felt was important about the sessions, how they helped her, and any other information she wanted to offer. Semi-structured questions were then employed to ensure that we fully explored social support via audioteleconferencing. Each interview was conducted by two of the investigators with a single participant. Strengths of this approach included a more complete follow-up on issues raised and a greater conversational style in the interview. It assisted us in gathering richly textured data. Women were given a choice where they would like to be interviewed depending somewhat on where they lived. One woman was interviewed in person in her home, five at their home via telephone, and five interviewed in person in a seminar room in the Health Sciences Centre.

With the participant's permission all interviews were audio taped and transcribed. A copy of each of the transcribed interviews was distributed among the researchers for data analysis. Each researcher performed a first level coding on the data and then met as a group to discuss the codes identified. Because this level of coding depends on remaining as close to the participants' words as possible, there was marked similarity between the initial codes identified. After initial agreement on codes each researcher took the codes and performed a second level coding. In this part of the analysis data is categorized and numbers of codes are generally reduced. Following the second level coding, or formation of broader categories, the researchers met again as a group to compare and agree on final category names. While categories were fairly similar, naming of the concept represented by the category showed slight variation. Consensus was reached by the researcher with experience in grounded theory analysis taking the three groups of categories from each of the researchers and drafting a beginning process for the group to discuss and approve. Diagrams were then constructed which represent the core variable (Figure 1) and substantive theory (Figure 2) that the researchers believe best represent the process of social support received via audio teleconferencing for women with breast cancer. Consensus was reached on the concepts and theory formation.

Eleven women volunteered for the study. They ranged in age from 30 to 78 years with a mean age of 52.09 years (SD = 12.28). They had been first diagnosed anywhere from one to thirty-seven years ago. All the women except one had a mastectomy and their stage of breast cancer varied widely. About half of the women reported lymph node involvement. Six of the women had received both radiation and

Figure 1: Faces and Voices: Social Support through an Audio Teleconferencing Network

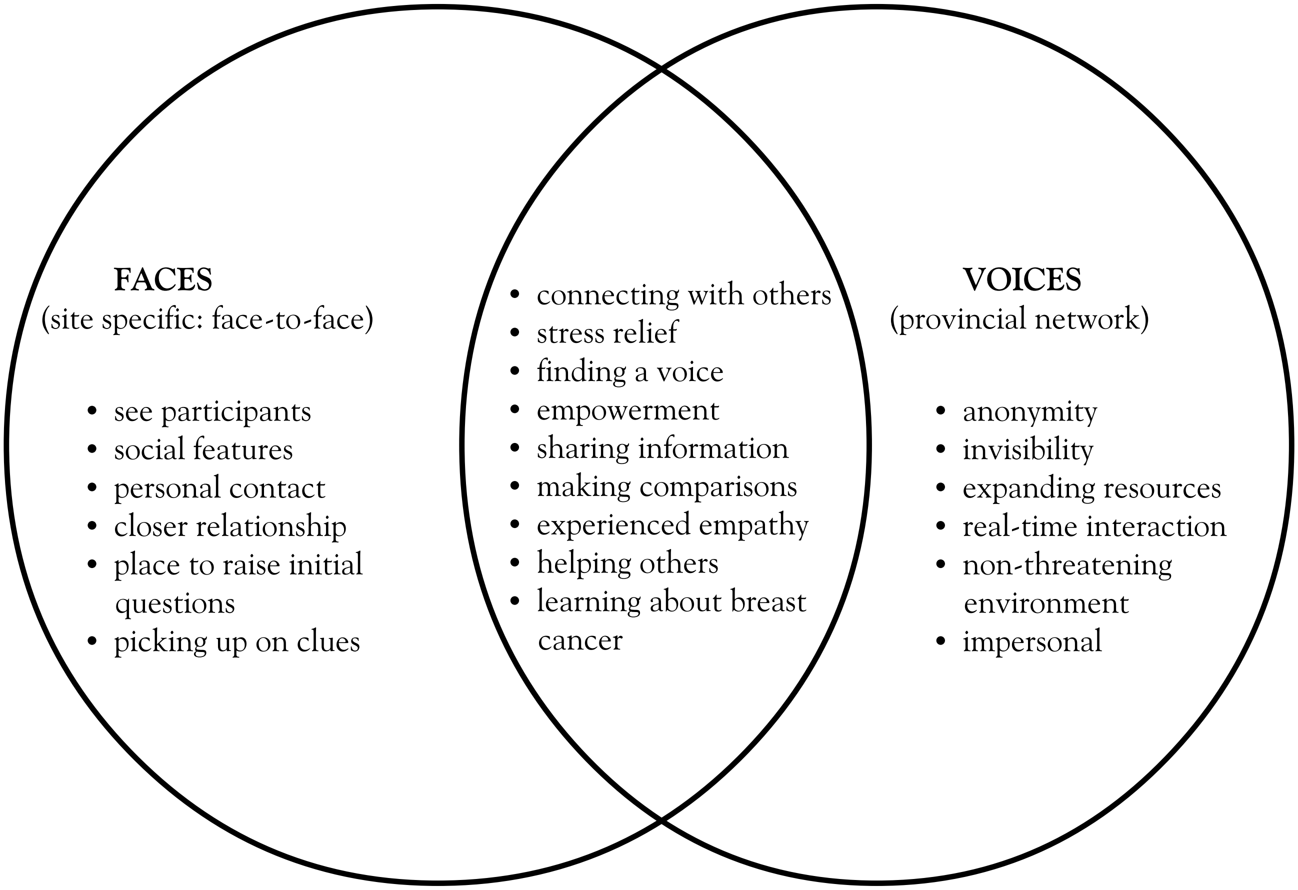
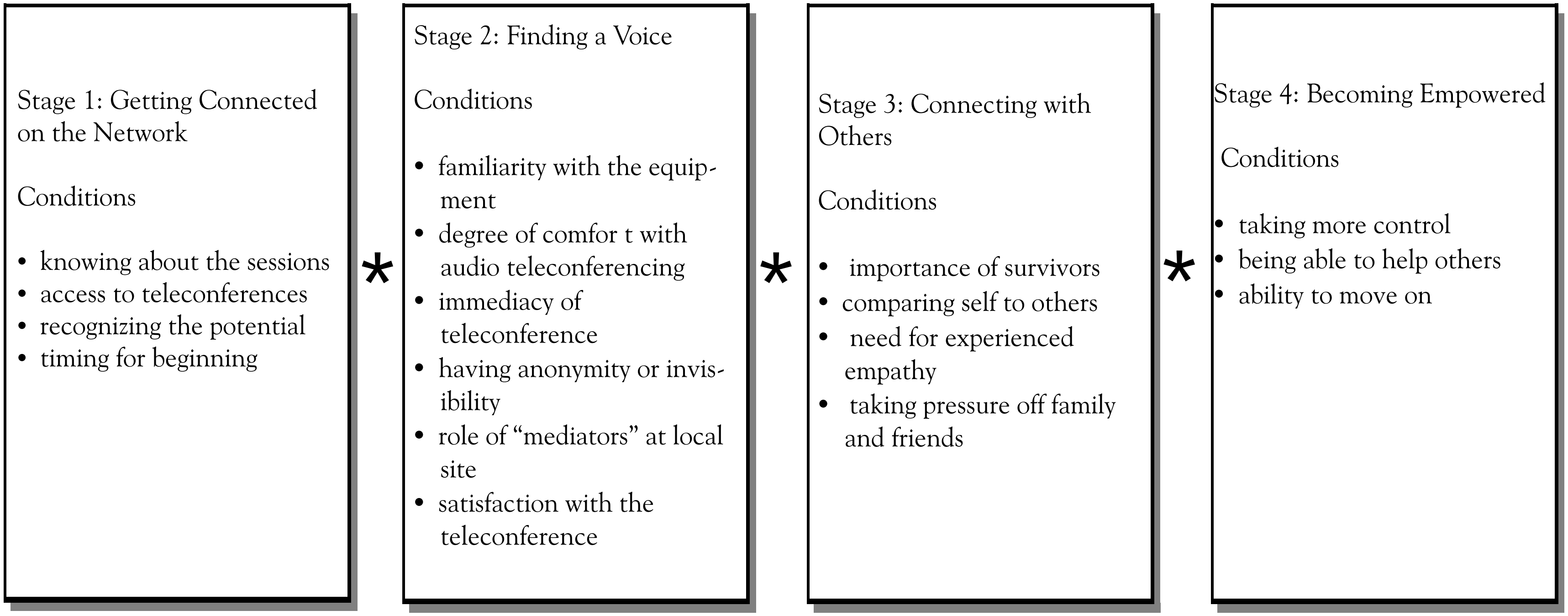


Figure 2: The Process and Conditions for Social Support through an Audio Teleconferencing Network for Breast Cancer Survivors



chemotherapy, one radiation, one chemotherapy, one a combination of radiation and tamoxifen, and one tamoxifen only. Most described themselves as having no evidence of disease at present. The participants came from diverse areas of the province.

1.4 PARTNERSHIPS

The partners for the project included the Newfoundland and Labrador Division of the Canadian Cancer Society (CCS) and Telemedicine Center, Memorial University of Newfoundland. Both of these partners were instrumental in helping the network link breast cancer survivors, first as a three-month pilot project and then through continued support for the initiative. For the present research their role has been that of support for the project and interest in obtaining an understanding of how support is delivered via audio teleconferencing and how the program may be improved and extended. CanSurmount volunteers assisted in recruiting participants for the study. One of the requirements of the Newfoundland and Labrador Division of the CCS is that the findings of our study assist in implementing new directions and decisions around the use of this medium for group support especially for those that fall within their mandate. Similarly, our second partner, Telemedicine Center, is interested in the use of technology to facilitate social support programmes. In keeping with the expectations of this partnership we will hold a forum where we will present the findings of our research and discuss the program implications of our study. In co-operation with our partners we will open this forum to a variety of groups and organizations who would benefit from the findings of our research.

1.5 EXPECTED OUTCOMES AND FINAL RESULTS

The expected outcome from the study was a description and explanation of the process of social support delivered via audio teleconferencing to women who have been diagnosed with breast cancer. Women who took part in the audio-teleconferencing obtained support both at the local site and the interactions that occurred there (faces), as well as through the system-wide network and the exchanges over this medium (voices). A number of participants made the distinction between these two levels of support and one women nicely summed it up as "*faces and voices*". The women were not only able to identify these two levels but were able to identify what type of support they received at each level and the overlap between the two. Faces was not a term used by many of the women, although a few used it to refer to the face-to-face contact in talking about the presence of others at the local teleconference studio location. Voices, however, was used by many to talk about their connection over the teleconference system. For a number of the women these voices were readily recognizable: "*I got to know familiar voices-got to know individual voices and to know people by voice*". Many of the women came to know the voices involved and listen for them when they attended the sessions. Others, although they acknowledged the voices represented real women, more importantly women like themselves, breast cancer survivors, they had a more disembodied stance; they remained voices. These participants for the most part were women who said they would have preferred a face-to-face support group in their local area. Thus it was felt that "faces and voices" accounted for most of the variation in the process of obtaining support and was identified as the core variable. Figure 1 demonstrates the type of support through faces and voices and the interface between the two.

The process of faces and voices consisted of four distinct but overlapping stages. These were identified as Stage 1: G*etting connected on* *the network*, Stage 2: *Finding a voice*, Stage 3: *Connecting with others*, and Stage 4: *Becoming empowered*. In each of these four stages certain conditions identified by our participants facilitated the woman's ability to receive social support. During the first stage the conditions were knowing about the sessions, access to teleconference, recognizing the potential, and timing for beginning. Both communication about the sessions and being able to have access to local teleconference sites were not always well facilitated. Additionally, women reported they had different expectations of what help they might be able to get via teleconference and these expectations were the motivation that was instrumental in their attendance. Timing in relation to diagnosis seemed to influence needs, as well as, emotional state, and hence, attendance. Flexibility around these two factors are important.

In the second stage, finding a voice, conditions identified by the women were familiarity with the equipment, degree of comfort with audio teleconferencing, immediacy of teleconference, having anonymity or invisibility, role of "mediators" at the local site, and satisfaction with the teleconference. A number of the women had used the teleconference system previously and they did not require learning time before they could take part. Others needed more time to gain familiarity. The women also varied in how comfortable they were in taking part in discussions and liked the aspect that active participation was under their control. Informational needs were one of the main motivating factors in attendance so immediacy of the teleconference in getting informational needs met was important. Anonymity or invisibility played a large role in taking part on the system as did the degree of satisfaction with this method of social support. One condition mentioned by some women at this stage, but not all, was the role of individuals who acted as mediators at the site. At some sites "voice" was achieved through this person who seemed to ask questions for other participants.

To achieve the third stage, connecting with others, critical conditions identified were the importance of survivors, comparing self to others, need for experienced empathy, and taking pressure off family and friends. Most of the women who participated in the teleconferencing sessions connected with each other whether at the local sites, network wide, or both. This connection, mainly of an emotional nature, was an important stage. Survivorship was important to connection and a number of women recounted when they first heard a long-term survivor speak and the impact this had on them and their outlook for the future. The women also spoke about comparisons they made with other women particularly in response to treatment or how they were feeling emotionally. For a number of the women an important part of the experience was that they were able to speak with someone who had the same condition as they did and that because of this vantage point the women *knew* they understood each other. This type of empathy was critical. Finally, the connection among the women on the system served an important role of taking pressure off family and friends; a burden the women did not want those close to them to bear exclusively even though they appreciated their family's and friend's support.

The final stage in the support process, becoming empowered, had as necessary conditions taking more control, being able to help others, and ability to move on. Women attributed a number of important changes in their lives to the audio teleconferencing sessions. For some women this was the ability to take more control in their lives, such as, asking their physicians for more information or a greater role in treatment decisions. It was a sense of the women controlling their disease rather than it controlling them. Some women described how they were able to help other women with breast cancer and they admitted that continuation in the sessions was mainly for those reasons. Finally, some women talked about how they could move on and that breast cancer no longer predominated their thoughts and actions. As one participant summed it up: "*I have come a long way*".

2.0 SCHEDULE OF ACTIVITIES

The goal of the research, i.e., to develop an explanatory model of the use of audio teleconferencing in the provision of social support to survivors of breast cancer among women living in rural Newfoundland, was accomplished. Through interactive, unstructured interviewing with the eleven women who agreed to take part in the study we were able to delineate the process of social support. This consisted of the main stages described already: *Getting connected on the network*, *Finding a voice*, *Connecting with others,* and *Becoming empowered*. Support through audio teleconferencing, such as used by these women, occurred at the local site (faces) and through the system-wide network (voices). Important contextual factors which accounted for the variation in the support received were feelings experienced by the women regarding their breast cancer, frequency of attendance at sessions, family's and friend's involvement, structure of the teleconference, and stage of the disease.

2.1 EVALUATION OF OBJECTIVES

The specific objectives were:

- To identify the process by which the use of audio teleconferencing provides social support and delineate the therapeutic factors in the process. The audio teleconferencing provided social support through site specific (faces) and network-wide (voices) mechanisms. These mechanisms permitted women in most instances to gather in small face-to-face groups where discussions extended beyond the actual session. However, they were also able to tap into wider experiences and information sharing by talking to women province-wide. Getting on the teleconferencing network offered them greater support than would be available in their home community. One of the main therapeutic factors in the process was experiential empathy; getting understanding from someone who "has been there". A number of women felt that the main benefit of the sessions was receiving this empathic response from other breast cancer survivors. A second therapeutic factor was meeting survivors and women described this as an "inspiration". It is as if these women received the hope that they needed in their breast cancer journey. Both of these therapeutic factors are supported in previous research on women with breast cancer (Breaden 1997; Burch 1997; Gambosi & Ulreich 1990). A third therapeutic factor was feeling empowered. The women felt that more decisions about their disease and treatment was within their control.
- To identify what support needs these women have. As in previous research on support needs those that our participants identified could be classified into informational and emotional support needs related to their breast cancer. Informational needs mainly related to treatment and resulting complications. Although the women did not use the information to a great extent in treatment decision-making, they did use it to compare reactions to treatment regimes. Moreover, they liked the immediacy of the information in that they could ask and receive information at the same session. One woman used the information she

received to find out about the logistics of where to stay when she came to the main cancer treatment centre. Others identified emotional needs such as survivorship, hearing about other women's experiences with breast cancer and their reactions, empathy from their peers, and a way of taking the burden off family and friends. This emotional support let the women know that how they were feeling was not so different from other women who had breast cancer and there was a comfort in that knowledge.

- To determine which needs are being met and which are not being met. The audio teleconferencing sessions were able to meet most of the women's needs and we asked this as a direct question to ensure it was covered. Informational needs were most easily met and these were met in a way that was very satisfactory to the participants. They generally rated this aspect of audio teleconferencing as a ten out of ten. In general the participants felt that there was no shortage of information about breast cancer from a number of sources, but what they felt the audio teleconferencing sessions enabled them to do was to discuss current information and also to ask specific questions and usually get an immediate answer to their questions. A number of women also felt their emotional needs were being met as well. However, the audio teleconferencing support sessions were not able to meet all women's needs. A few women would have preferred more face-to-face contact with other survivors but the particular area where they were located either did not have or they were unable to recruit other women with breast cancer. Others would have preferred a discussion of more personal issues than seemed to occur. Some women indicated that a more structured approach to the sessions might be helpful although most felt they liked the fact they could mainly structure the interactions. Generally, there were not many negative comments expressed by the participants about the teleconferencing support.
- To identify the role that the technology plays in providing the support. Gender is known to play an important role in the use of technology (Kramare 1988) and while it can be a great facilitator for enhancing our support capabilities, it also can be an inhibitor. Technology did permit women who were geographically separated to transcend distance. It also allowed participation and participants to be mobile. If a woman had to go to the main treatment centre she did not have to withdraw from her support group as might have occurred if she left the local area. She could still maintain connection with the support group by attending at a different site. While most of the women liked the anonymity that the technology gave them, some also felt the technology and the anonymity that seemed to be a part of it, did not lend itself as well to making emotional connection. It was a little inhibiting for some women to speak into a microphone. They were aware of the presence of the technology but most were able to transcend it.

2.2 EVALUATION OF PROJECT

No significant problems occurred in the project and the researchers easily were able to meet the stated objectives. The number of participants was towards the lower end at eleven whereas we hoped to recruit between 12 to 15 or until data saturation was obtained. The number of participants was sufficient and we felt comfortable that saturation did occur.

While we did have variation in the data we were able to account for the conditions that contributed to this variation. The evaluation methods we selected to confirm our findings were those of comprehensiveness and completeness. Comprehensiveness refers to whether the model covers the diversity of situations suggested by the participants. Through a constant comparative method of analysis by the three researchers all data were able to be incorporated into the model. While variation was present, conditions that contributed to this variation were identified. Completeness refers to outlining the support process in full. This was evaluated in two ways. First, we went back to the literature and related our findings to that on social support and breast cancer and also to that of teleconferencing support groups. There were a number of similarities in our findings and that of previous studies. Second, we will present our findings to survivors of breast cancer who have taken part in our study, as well as, those who have not at a public forum and get feedback as to how complete they believe our findings are in describing social support via audio teleconferencing.

3.0 DISSEMINATION PLAN AND KNOWLEDGE SHARING

A variety of methods have been used or are being planned and developed for disseminating the findings and information related to the use of teleconferencing technology as a mechanism for providing social support programming to rural women with breast cancer. The purpose of these methods is to heighten awareness among various populations, including researchers, policy makers, women with breast cancer, non-governmental organizations, and grassroots health organizations of the utility and effectiveness of teleconferencing support for breast cancer survivors and patients.

3.1 WORLD WIDE WEB SITE

We will also develop a WWW site which will contain a description of our project and a copy of the final report. This site will contain links to and from sites that are related to breast cancer.

The development of the Internet started a revolution in communications that has provided new opportunities for disseminating health information. Originally, the Internet began as a communication link among computer facilities and departments, accessible only to those comfortable with computer language. It became user-friendly with the development of the World Wide Web (WWW or Web), a standard for the presentation and delivery of various types of electronic information. The Web has brought a graphical user interface to the previously text-only Internet. This new set of standards provides users with a more efficient mechanism for utilizing the Internet through browser software via a click and point interface, enabling one document to contain pointers to and from many others.

The Web links computers and users from around the world for communication and interaction. Anyone with access to a computer, an Internet connection, and a Web browser can access information published on the WWW. As well, in recent years the federal government has announced strategic initiatives to see that all rural and urban communities in Canada have access to the Internet and the WWW through community-based public access sites. Many of these sites are currently in place in community libraries, municipal or provincial buildings, schools and community health clinics. These public access sites will enable many persons without a home computer to access the Web.

Today, most people think of the World Wide Web (WWW) as an ideal environment for information publishing. Increasingly, Universities are using the WWW to disseminate a variety of information to various target audiences. As a medium for disseminating health information to patients, consumers, and health professionals, the Web is particularly useful. Websites can be quickly accessed and updated, and individuals can navigate the graphical-user interface of the Web fairly easily. An informational Website will be developed for this project containing a description of the study and a copy of the project's final report. The site will also contain reciprocal links to and from other Websites associated with breast cancer.

3.2 AWARENESS FORUM

Public forums are used when large groups of people meet for the purpose of diffusion of knowledge, information, or opinion. The forum tends to be semiformal in nature, yet is directed by a moderator who is responsible for guiding discussion. During a forum the audience is encouraged to raise and discuss issues, make comments, offer information, or ask questions of the resource person(s).

An "Awareness Forum" will be held in order to disseminate the results of the project to stakeholders and policy makers in the local community. One of the three investigators will act as a moderator for the forum, while the two other investigators will act as resource persons. The investigator/moderator will be responsible for introducing the program and guiding discussion. The investigator/resource persons will be responsible for supplying information, answering questions, stimulating audience thinking, and offering insights and ideas for continued discussion. Videoconferencing technology will be used to connect with stakeholders from outside the immediate St. John's regions. This will enable the investigators to involve groups at a provincial level, and possibly regional, national or internationally, in the forum discussion.

The audience for this awareness forum will include invited guests from non-governmental organizations, health care agencies, and provincial and federal government departments. Special invitations will also be extended to women who participated in the study, participants in the teleconferencing support program, agencies and not-for-profit health, patient and family support agencies.

3.3 RESEARCH PUBLICATIONS

Several papers have already been published related to the Breast Cancer Teleconferencing Support Network:

> Curran, V. & Church, J.G. 1998. Not alone: peer support through audio teleconferencing for rural women with breast cancer. *CMAJ*, 159(4), 379-381.
>
> Curran, V. & Church, J.G. 1999. A study of rural women's satisfaction with a breast cancer self-help network. *Journal of Telemedicine and Telecare*, 5, 47-54.

The intention of the investigators is to prepare further manuscripts documenting the findings of this particular study for publication in appropriate peer-reviewed journals. These manuscripts will document in detail the purpose of the study, the methodology used for collecting participant perceptions and experiences, the results and findings of the study, and the implications of the findings for the provision of technology-based social support. As well, a poster display will be developed and used to illustrate the findings of the study at a variety of peer meetings over the next year.

3.4 PRESENTATIONS

The investigators have already presented the findings of their work at professional and academic meetings and conferences over the past year, and will target appropriate conferences in the upcoming months as well in order to disseminate the findings of the study:

> Breast Cancer: Myths & Realities: "Communication Technologies and Virtual Breast Cancer Support Communities." Vancouver, B.C., February, 1999.
>
> World Conference on Breast Cancer: "'Voices and Faces': A Breast Cancer Support Community for Rural Women Through Audio Teleconferencing Technology." Ottawa, Ont., July, 1999.
>
> Association of Registered Nurses of Newfoundland & Newfoundland & Labrador Nurses' Union "Nursing & Informatics: A Vehicle to Strengthen Client Care. Meeting the Needs of Women with Breast Cancer Through Technology." St John's, NF, May 1999

3.5 BREAST CANCER SURVIVORS

Our target group will be informed through a number of mechanisms. Each participant in the study who would like a copy of a report will be sent one. Participants and other breast cancer survivors will be invited to the public forum and made aware of the WWW site. The latter will make the findings widely available to a greater number of women with breast cancer.

4.0 SUMMARY OF EXPECTED OUTCOMES AND IMPACT OF PROJECT

Our project addressed the dual research programs of MCEWH, Program 1: Women's Perceptions of Determinants of Health, but most directly, Program 2: Social Determinants of Health of Marginalized Women Living in Disadvantaged Circumstances (see, Research Fact Sheet, Appendix A). Although one of the identified determinants of health is social support networks (Federal, Provincial, and Territorial Advisory Committee on Population Health 1994, 1996), at present a gap in access to psychosocial support programs appears to exist in many rural areas (Bushy 1993; Weinberg et al. 1995). For rural women with illnesses, this gap in health and psychosocial services program access has unique implications for their general psychological health. When rural women are diagnosed with an illness, the psychosocial support networks that are quite prevalent in many urban communities, and often taken for granted, are few and far between. Psychosocial stressors related to learning about one's diagnosis, managing treatment, and long-term prognoses are more pronounced for people living in rural areas because of limited services (Rounds et al. 1991).

Results from several studies suggest that individuals who participate in self-help support group interventions and have strong social ties live longer, have better physical and mental health, and show better recovery and adjustment characteristics than those without such ties and interventions (Dunkell-Schetter 1984; Spiegel et al. 1989; Spiegel et al. 1981). The immediate social networks of family, relatives, friends, and neighbors are important social ties for individuals with cancer. However, self-help and mutual support group programs often give individuals a certain level of support that cannot come from close family members. Support from families, friends, and communities is thought to enhance health and while these supports are still important to women with breast cancer, the disease itself imposes certain limitations on these traditional sources of social support. Cancer patients are often unable to receive sufficient support from family members and friends because the disease disrupts open communication and patients may restrict the concerns expressed to family members (Dunkel-Schetter 1984; Weinberg et al. 1996). Survivors of breast cancer require additional support systems to help them with another determinant of health; coping skills. Moreover, the situation for rural women may be worse as they consistently identify a smaller social network to which they may turn for support and information (Bushy 1993).

Self-help psychosocial peer support groups bring together individuals in similar situations to share experiences with each other, to learn from and teach each other, and to create new social networks (Chesney et al. 1989; Andersen 1992; Manne and Zautra 1989; Weinberg et al. 1996). Self-help social support groups can lessen some of the distress experienced by cancer patients, and can increase a sense of self-determination (Rittner and Hammons 1992; Weinberg et al. 1996). Group work offers those with an illness opportunity for “therapeutic interactions, cooperation, education, support, reinforcement, feedback, and the testing of perceptions” (Rittner and Hammons 1992: 61). Support groups provide participants with a network of understanding and supportive people. They can benefit patients by enhancing affect toward the disease, providing support and information from others who have experienced the same circumstances and treatments, and offering strategies for managing difficult situations and stress (Cain et al. 1986; Spiegel et al. 1989).

In researching social support as it contributes to women’s coping skills in dealing with breast cancer our research outcomes contribute to the mandates of the MCEWH as follows:

Generating new knowledge. Our study contributes to a greater understanding of an innovative social support programme for rural women and how we can foster connection among women in diverse areas in need of support. It also contributes to an understanding of how women use technology to improve their well-being. Additionally, it identifies conditions that foster or inhibit the kind of social support that women with breast cancer receive.

- We have frequently operated, in the past, from the assumption that women in rural areas, while distanced from formal means of social support, have greater informal means of support through family and friends and community cohesiveness, and the latter compensates for the lack of formal support services. With the help of our participants our study clearly shows this assumption is not supported. These women talked about the effects of the diagnosis on their spouses or other family members and how some of these people felt. They did not feel that family and friends, no matter how supportive, could understand what they were experiencing because you really had to be there to understand. They believed it was very important to talk with other women who knew what living with breast cancer was like to help them deal with the tremendous emotional upheaval they were going through: *It was at a point* [early in the disease process] *that my family were there for me 100%, but . . talking to survivors and people who were going through it at the same time . . . that was what I needed and it was there, so I was very thankful for that.* Others spoke of not wanting their communities “to know all my business”, and spoke of how the teleconferencing network was invaluable in lessening both family and community burdens of dealing with the disease process. The rural women were concerned about burdens they may put on family, friends and community because of their breast cancer and valued the opportunity to talk with other survivors.
- Empathy is suggested as a strategy for health professionals to use in meeting patient’s emotional needs. The women in our study challenged how well health professionals can meet the need for

empathy. They felt that the support they received from other women with breast cancer was qualitatively different from that they received from individuals who do not have the disease. They wanted to talk to women who have been through a similar experience to themselves but more importantly they wanted to know that other women survived breast cancer. This has important program implications not only for health professionals but for how we structure cancer support groups. One of the obvious means of solving formal support in smaller communities is to combine all cancer survivors in one group. The women we interviewed provide a caution to this approach. While they did concede there are some commonalities across cancers, the stronger belief was that the needs and concerns of breast cancer survivors are different. Optimal support, therefore, comes from a group of women composed of breast cancer survivors. Moreover, they appreciated having access to long-term survivors as well as women in active treatment. They also appreciated the presence of a facilitator who was knowledgeable about breast cancer and could discuss with them the latest in treatment options, on-going or up-coming clinical trials, or breast cancer "news" presented in the media.

Providing policy advice. Women with breast cancer who live in rural areas often are unable to avail of the same services that women in urban areas have access to, yet they have many of the same needs. Support needs are one such service. The findings from our study have a number of important policy and program implications.

- Our research clearly demonstrates the efficacy of using teleconferencing technology as an innovative mechanism of providing social support at a distance to remote and rural women. The findings from the present study demonstrate that women who are geographically distant from services are able to get this service through the use of technology. Audio teleconferencing can provide informational and emotional in a cost effective and satisfactory manner.
- The social support needs of all women with breast cancer, rural or otherwise, require the same status as usually attributed to the treatment of a physical illness. An education and lobbying campaign aimed at health professionals, in particular, surgeons, radiologists, and oncologists, highlighting this need and its importance should be carried out. Not only will this help those women directly in dealing with the health care system. But will aid in making social support programs more generally available, and women more informed as to where they may be obtained.

5.0 IMPACT ON POLICY-MAKING

The findings of this project have a number of important implications for breast cancer survivors and support programs for women in rural areas (see Policy Fact Sheet, Appendix B). There are also some policy implications for how health care may be extended to people in outlying areas. One of the challenges of a modern health care system is to overcome the barrier of distance in delivering cost-effective health care in a newly restructured service. This study has demonstrated that the communication technology of audio teleconferencing can offer alternative and innovative bridging mechanisms which overcome the challenges of geographic isolation, and provide rural women with much needed psychosocial support programming. The findings of this research demonstrates why audio teleconferencing can overcome some of these barriers and how the technology can be used effectively as a means for providing this form of health care to a target population of rural women. The results of our interviews revealed that women participating in the program reported that the social support they received was helpful in coping with the stressors they experienced as a result of living with breast cancer. It is our recommendation that programs of this type using similar technologies be supported for addressing the social support needs of persons living in rural and remote communities. More generally, the use of telephone and audio teleconferencing technologies should be encouraged more widely for facilitating and providing information and support to people in need in rural settings where such services might be beneficial.

Isolated rural women with breast cancer benefited from participating in an audio teleconferencing social support program in terms of decreased perceptions of isolation, enhanced "experienced empathy", and increased feelings of hope and being able to cope emotionally with their illness. They found that an audio teleconferencing social support network was an effective means for disseminating and interpreting information, receiving and providing emotional support, sharing hopes and concerns, and feeling not alone in learning to cope with their illness. For these rural women, audio teleconferencing enabled them to transcend their geographic and social isolation, and to connect with others sharing similar concerns, fears and experiences. In addition, these women perceived that audio teleconferencing offered anonymity, real-time interaction, and was relatively easy to use and inexpensive.

Although the delivery of health care services and programs to rural and remote communities has improved significantly during the twentieth century, the scope of acute hospital care has focussed to a large extent on the treatment and management of a person's physical illness. Little attention or resources have been extended to therapy related to the psychosocial health of the individual and the patient's ability to cope with the stressors related to illness. In many urban communities, population density has made it possible to offer some social support programming. However, rural persons are disadvantaged as it relates to availing of the therapeutic benefits of such programs because of distance and isolation. The outcomes of this study confirmed that rural women with breast cancer lacked access to the services and programs to adequately address their psychosocial support needs. Current programming, or lack thereof in rural and remote communities, was not addressing the needs of this population of women. The results of our project demonstrated that a social support program for rural women with breast cancer can be successfully facilitated by means of an audio teleconferencing network. The use of this technology to connect rural women with breast cancer can address many of the emotional and therapeutic needs related to coping with this illness.

Program planning, promotion, recruitment, and organization are key activities in the development and implementation of a successful audio teleconferencing social support program. Awareness of the availability of these programs, avenues for making connection with people involved in delivering the program, and the promotion of sites and locations for participating are necessary program delivery tasks. Rural women need to be made aware that these sessions are available to them. It is essential then to develop logistical and coordination mechanisms for promoting programs to participants and health care providers, recruiting participants, and liaising with participants as they initiate participation in the program. Health care facilities or educational institutions where the teleconferencing sites are located need to stop creating barriers that prevent women access to the teleconference sites. By removing these barriers and facilitating in any way access to the teleconference site, such initiatives would go a long way in creating a welcoming environment. All personnel at the local teleconference site need to be informed about the importance of these sessions to breast cancer survivors and make an effort to welcome women and their support persons to the teleconferencing room. In addition, it is necessary to provide support and orientation to facilitators of audio teleconferencing social support programs. Training must focus on the differences and peculiarities of communication via teleconferencing systems, skills in building support programs via technology-based systems, and teleconferencing facilitation skills. There is also a need to provide an orientation to the equipment for women who are first time participants in teleconferencing programming.

Another program implication is to allow women to decide when it is the optimal time for their attendance at such distance support programs. This could be addressed by providing women with information about the program, what the purpose of the program is, who attends, and the type of discussion that occurs as early as possible after their diagnosis. Promotional material could be used to disseminate information about the program, but another avenue of promotion which could be explored would include meeting with and talking to other women who have attended the program in the past. The main emphasis of such encounters would be on welcoming while not placing any form of pressure on the woman to attend until she is ready. For the women in the study their perceived readiness of the optimal time to attend varied somewhat, although some women mentioned that they wished they had known about the program earlier so they could have taken advantage of the support at an earlier time in their diagnosis.

The flexibility of attendance at a teleconference program was valued by the women, therefore, they need to be allowed to come and go as they feel necessary. Women should feel in control, to decide on the level of participation so that decision-making remains within her control. Other important aspects of successful social support program delivery via audio teleconferencing included the preservation of the anonymity of the teleconference for those who value this. Participants should be reminded that they do not need to identify themselves by their personal names. Facilitators should enable the women to decide on how the sessions are structured. However, an unstructured format appeared to work well because the women were able to address the problems and concerns which were salient to them. Facilitators should promote the establishment of many-to-many connections between participants in the teleconference and the sharing of experiences, while not forcing or coercing participation.

While the composition of the group is not entirely within the control of the facilitator, if at all possible these type of programs should include the involvement of long-term survivors, and women who desire to help, as well as those who want to receive it. In a promotional campaign it would be advantageous to advertise that the program offers women an opportunity to both receive and give help. Survivors should also be targeted as participants for the program. These programs should also continue to provide up-to-date information on breast cancer and treatment. This was a major advantage of the program which was cited by a majority of the women who were interviewed.

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APPENDIX A: RESEARCH FACT SHEET

Research Finding #1: Rural women received emotional and educational support and information from both the network-wide teleconference system ("voices"), and the face-to-face interactions at respective sites ("faces").

Research Finding #2: "Voices" and "faces" enabled rural women to transcend their geographic and social isolation and to connect with others through experienced empathy (i.e., that from peers with breast cancer), a critical aspect of emotional support.

Research Finding #3: Audio teleconferencing support offered rural women with breast cancer anonymity, real-time interaction, and was very cost-effective and relatively easy to use. Problems related to this form of communication could, however, arise as a result of lack of non-verbal cues and face-to-face contact.

Research Finding #4: Women who participated commonly reported initial difficulties in finding out about the network, where teleconferencing sites were located, how to go about taking part, and accessing the physical teleconference site.

RECOMMENDATIONS FOR FUTURE RESEARCH

1. Measure the impact of participation in audio teleconferencing programs upon the health outcomes of participants.
2. Compare different program structures (open-ended vs. psycho-educational goal-based) and technologies (video teleconferencing vs. audio teleconferencing), and their effectiveness in affecting emotional states and reported satisfaction levels of participants.
3. Assess methods for best recruiting geographically and socially isolated participants for audio teleconferencing social support programming, and what attributes or characteristics of participants and facilitators are most likely to lead to success or satisfaction.
4. Compare women with other conditions or diseases and their experiences of social support via audio teleconferencing.

APPENDIX B: POLICY FACT SHEET

Major Finding #1: Rural women received emotional and educational support and information from both the network-wide teleconference system (“voices”), and the face-to-face interactions at respective sites (“faces”).

Policy/Program Implications with Major Finding #1

A. Continue the use of audio teleconferencing system for delivering social support programs.

B. Target rural and geographically remote women for audio teleconferencing social support programs.

Major Finding #2: “Voices” and “faces” enabled rural women to transcend their geographic and social isolation and to connect with others through experienced empathy (i.e., that from peers with breast cancer), a critical aspect of emotional support.

Policy/Program Implications with Major Finding #2

A. Ensure that women at different stages of breast cancer, in particular, long-term survivors, take part in the support network.

Major Finding #3: Audio teleconferencing support offered rural women with breast cancer anonymity, real-time interaction, and was very cost-effective and relatively easy to use. Problems related to this form of communication could, however, arise as a result of lack of non-verbal cues and face-to-face contact.

Policy/Program Implications with Major Finding #3

A. Adapt the process of facilitating and/or moderating social support to the medium of audio teleconferencing.

B. Provide support and orientation to facilitators of audio teleconferencing social support programs.

C. Provide orientation and support to the participants in audio teleconferencing social support programs.

Major Finding #4: Women who participated commonly reported initial difficulties in finding out about the network, where teleconferencing sites were located, how to go about taking part, and accessing the physical teleconference site.

Policy/Program Implications with Major Finding #4

A. Develop program coordination mechanisms for promoting the program to participants and health care providers, recruiting participants, and liaising with participants as they initiate in the program.

B. Liaise with local teleconference site managers and provide support in setting up the local site as well as the system-wide network.