



BC Cancer Agency
CARE & RESEARCH

**Improving Access to Psychosocial/Supportive Care:
An Investigation of the Potential of Technology**

**British Columbia Cancer Agency
Sociobehavioural Research Centre**

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Executive Summary

The cancer care system operating in Canada today faces geographic barriers, financial constraints, and a fragmentation between provincial cancer centres and health authorities. This situation challenges our ability to provide our diverse population with universal and equitable access to psychosocial care to our diverse population.

Telecommunication technologies are currently embraced by the public and private sectors as a means to transmit information, promote education, and maintain relationships over small and large distances. This report explores the potential of these technologies to improve access to psychosocial care for cancer patients and their families. In order to assess the potential of technology for addressing these issues in psycho-oncology, a literature review and environmental scan were conducted.

Research Questions:

- ❑ *Types of technology used:* What is the range of technologies that are used to deliver psychosocial/supportive care? What is known about their effectiveness?
- ❑ *Potential use of technology:* What is the interest in using communication technologies for psychosocial care in Canada? Who do support workers view as most able to benefit from these technologies?
- ❑ *Readiness for organizational uptake:* What are the issues and concerns identified by researchers and clinicians? What capabilities are needed to carry out technology-based programs of support? What barriers exist with regards to providing psychosocial care using health technology?

Key Findings:

- ❑ The technologies used to deliver psychosocial care in oncology include teleconferencing, videoconferencing, electronic support groups, and comprehensive computer systems. Teleconferencing was the most widely used technology in Canada, according to key informants, followed by videoconferencing.
- ❑ To some extent, all of the technologies investigated have value and also limitations. What is clear, however, is that there is a paucity of outcome studies and randomized trials. More studies need to be conducted so that evidence-based practices are implemented.

- ❑ People who would benefit from improved access to psychosocial care include individuals who face geographic, physical status, and time barriers. People who need specialized programs or those uncomfortable with face-to-face services may also benefit. Traditionally underserved groups such as ethnic minorities and those with lower socio-economic status may also benefit.
- ❑ Issues to consider for delivering technologically assisted psychosocial care include funding, human and technical resources, ethical and legal concerns, equality of access, comfort with the technology, and client awareness.
- ❑ Planning for the development and integration of communication technologies at the service level in cancer care is largely underdeveloped and lacks coordination between provinces

Recommendations:

- ❑ Teleconferencing is an equitable and cost-effective technology that has the potential for immediate uptake. Standards and guidelines should be identified and adopted and patients should be offered the opportunity to receive care this way.
- ❑ Videoconferencing is a viable option when existing telehealth videoconferencing networks are already in place. Funding for technology staff needs to be increased.
- ❑ Computer applications such as websites should expand to include practical and psychosocial/educational material so that patients and families can do more to support themselves. Further exploration of facilitated bulletin boards and real-time electronic support groups is needed.
- ❑ Priority must be placed on obtaining evidence for the effectiveness of communication technologies in improving supportive/psychosocial care. Clinical trials must be performed with samples from populations most in need of improved access.
- ❑ A national approach to planning and implementation of communication technologies for service delivery requires a cooperative approach and should be coordinated, ideally through a national body.

1.0 Introduction

Progress in combating cancer includes consideration of psychological functioning and quality of life. In spite of the recognized benefit of psychosocial interventions for patients, families and the health care system, availability and accessibility of support services is limited. The cancer care system faces geographic barriers, financial resource constraints and a fragmentation between provincial cancer centres and health authorities. This challenges our ability to provide Canada's diverse population with universal and equitable access to psychosocial care.

Research has demonstrated that psychosocial care significantly contributes to reducing the burden of cancer by improving adjustment to the disease and other dimensions of quality of life (Anderson, 1992; Cunningham, 2000; Fawzy, Fawzy, Arndt, & Pasnau, 1995; Meyer & Mark, 1995; Spiegel, 2001; Trijsburg, van Knippenberg, & Rijpma, 1992). Furthermore, there is evidence that psychosocial interventions can contribute to reduced costs in the overall care of the patient (Carlson & Bultz 2002; Lane, 1998; Linden, Stossel, & Maurice, 1996).

Nevertheless, resource allocation for supportive care programs faces significant barriers as health service providers face budget constraints. Creative, effective and efficient approaches need to be explored to improve access to care. This is particularly the case in rural areas where funding, expertise and geographical barriers affect the availability of supportive care.

Communication technologies are currently embraced by the public and private sectors as a means to transmit information, promote education and maintain relationships over small and large distances. Health Canada advocates the use communications technology for the delivery of health care and health-related services and information, in a strategy known as *telehealth* (Office of Health and the Information Highway, 2000). Telehealth is not meant to replace human contact; instead, its value lies in augmenting access to care (Ho, 2000).

Telehealth originated over thirty years ago and has grown considerably in the past few years (Office of Health and the Information Highway, 2000). It encompasses the transmission of information using two different methodologies: 1. *store and forward*, which involves capturing information and reviewing it later (e.g., email) and 2. *real-time interaction*, which involves immediate and synchronous sending and receiving of information (e.g., telephone, videoconference) (Siden, Young, Starr, & Tredwell, 2001). Teleconferencing, videoconferencing, online forums, and digital formats such as CD ROMS and DVDs are among the many ways telehealth is currently utilized by patients and families to receive psychosocial support and exchange information with health care providers.

Specific programs include:

- the use of CD-ROMs for education about decision-making strategies regarding alternative communication for disabled individuals and their families (Vanbiervliet & Parette, 2002);
- a computer system to reduce caregivers' social isolation and increase decision-making confidence for caregivers of Alzheimers patients (Brennan, Moore, & Smyth, 1991; McGuire, 1998);
- videotapes and telephone calls to augment services for tobacco cessation (Lichtenstein, Hollis, Severson, & Stevens, 1996); psychoeducational videotapes to reduce risk and promote resiliency in children of depressed parents (Butler, Budman, & Beardslee, 2000);
- telephone support groups for caregivers of persons with brain injury (Brown et al., 1999); and
- phone-call support for patients with chronic illness (Roberts et al., 1995).

The interactive environments created by the use of telehealth are a powerful source for developing knowledge, self-efficacy, and problem-solving skills (Street, 2003).

While telehealth demonstrates promise for delivering supportive interventions, the integration of telecommunications technology in current care programs is underdeveloped. The potential for expanding the use and quality of multiple technologies is considerable, given that information transmitting devices continue to develop and high speed high bandwidth transmission is becoming increasingly available (Finkelstein & Friedman, 2000). With its potential to reach rural, elderly, homebound, and ethnically diverse Canadians, telehealth is an opportunity to increase the access to information, education, and emotional support across the cancer continuum.

Prior to making recommendations about the future application of communication technologies to psychosocial/supportive care in oncology, several issues need to be investigated.

- ❑ *Types of technology used:* What is the range of technologies that are used to deliver psychosocial/supportive care?
- ❑ *Evaluation of technologies:* Which technologies are clinically effective? Which are not?
- ❑ *Potential use of technology:* What the willingness of people from diverse population groups to use technology? Who is most in need of improved access to psychosocial care?
- ❑ *Issues and concern around implementation:* What capabilities are needed to carry out technology-based programs of support? What issues, concerns and barriers exist with regards to providing psychosocial care using communication technologies? Which technologies are acceptable or appropriate for patients, families and other consumers?

By conducting a literature review and an environmental scan, the current project investigated these issues and offers recommendations about the future use of technology in delivering psychosocial care to cancer patients and their families. The project scope did not include the use of technology with respect to information provision.

2.0 Methodology

2.1 Literature Review of Empirical Research

A literature review was conducted to understand the most recent work in the area, including methodology and evidence for effectiveness. The literature review is based primarily on articles obtained from literature searches of electronic library databases.

Procedure: Searches of PsycInfo, MEDLINE, and CINAHL databases were performed for the period 1990 to 2004. Search terms included social support, psychosocial support, supportive care, telehealth, video, audio, telephone, computer, Internet, technology, and cancer. Relevant publications known to members of the project team were also reviewed. The literature review focussed primarily on articles dealing with oncology. Due to the nature of psychosocial care, however, some work from the fields of mental health and psychiatry was also included.

2.2 Environmental Scan

An environmental scan was conducted to (1) learn about current psychosocial programs that utilize technology; and (2) obtain the perspectives of knowledgeable individuals about the current use of technology to deliver psychosocial care and about the future of telecommunication technology in this area. The scan involved interviewing individuals from across North America, each with expertise in some area of psychosocial care and technology. The project team generated an initial list of key informants that was comprised of: 1) support providers, with an attempt to involve health/cancer agencies from the various Canadian provinces; 2) researchers and research consultants; 3) technology specialists; and 4) patients or patient advocates. The environmental scan thus sought to obtain perspectives from a variety of individuals. Additional informants were identified through the interview process by suggestions made from interviewees.

Procedure: An introductory letter about the project and the interview was sent to 34 individuals. Of these, two individuals were interested in participating but could not due to scheduling difficulties, and suggested another person in lieu. Two other people could not be scheduled for an interview. Another two individuals provided contacts for people they felt would be better candidates to provide information. Five individuals could not be contacted. One person did not wish to participate and one person was not a suitable candidate. In total, 21 interviews were conducted with key informants. A summary of the key informants' characteristics is provided in Table 1.

Table 1 Characteristics of Key Informants

<i>Number and type of informant</i>	<i>Location</i>
Support providers (n = 13) <ul style="list-style-type: none"> ▪ 8 directors of programs in hospitals or cancer organizations ▪ 4 providers of a specific psychosocial program involving technology ▪ 1 librarian 	British Columbia, Alberta, Manitoba, Ontario, Quebec, and Newfoundland
Consultants/researchers (n = 5)	Manitoba, Ontario, California, and Wisconsin, Hawaii
Information technologists (n = 2)	British Columbia
Survivors/patient advocates (n = 3) <ul style="list-style-type: none"> ▪ 2 survivors ▪ 1 parent 	British Columbia, Ontario, and New York

A semi-structured format was developed for key informant interviews. The interview questions aimed to investigate the use of communications technology for psychosocial care with respect to the present and the future clinical work. Questions were tailored to the background of the key informant. The interview schedule for support providers is reproduced in Appendix A.

Support providers were asked about their current use of technologies in providing psychosocial/supportive care as well as their interest in implementing technology-based programs in the future. Researchers and consultants were asked about their particular programs and views about the future of health technology in delivering psychosocial care. Questions for patients/advocates, on the other hand, inquired about any psychosocial care programs they used that involved technology and their interest in using technology-based programs. Questions for technology support individuals explored their knowledge of various technologies and the capabilities required to implement them.

Interviews with key informants occurred over the telephone in all cases but one. The duration of the interviews ranged from approximately 30 to 60 minutes. All interviews were conducted by the project coordinator and were audiotaped with the permission of the interviewee. Notes from the interviews were recorded and organized according to their relevance to the research questions. Results of the key informant interviews are denoted as such in the report. Information derived from interviews with cancer survivors/advocates are not reported in detail in the current report due to the small sample size.

3.0 Results I - Empirical Research on Technology and Psychosocial Care

A primary objective of this investigation was to survey the scope of communication technologies in psychosocial care, and to determine which approaches were effective. The outcome of the research literature review is reported in Section 3.0 and divided into research on 1. teleconferencing, 2. videoconferencing and 3. computer technologies.

3.1 Teleconferencing

The telephone is the oldest and the most common telecommunication technology available. The most familiar use of the telephone is conversation between two people who are in two different locations. Communication among several people in two or more locations is called teleconferencing and is usually aided by the use of speakerphones.

Teleconferencing as a medium for the delivery of psychosocial care has both advantages and disadvantages (Gotay & Bottomley, 1998; Marcus et al., 2002). The telephone equipment required is almost universally available and affordable compared to other technologies. Teleconferencing has the potential to reduce barriers caused by geography, transportation, physical status, or lack of local services. Thus, individuals who live in rural or remote areas where live services may be unavailable, or those who are housebound or too ill to access face-to-face services, could have access to services. In addition, the privacy and anonymity associated with teleconferencing makes it a suitable medium for groups who tend to be less comfortable with face-to-face settings, such as males, the elderly, and certain ethnic groups. Interestingly, the anonymity of telephone communication, although preferred by some, is seen as a disadvantage for others. The lack of visual cues is also a possible disadvantage. Lastly, teleconferencing is unsuitable for those with hearing problems or for those who do not have a telephone.

Individual support

Telephone interventions involving psychosocial care in oncology most often consist of one-on-one counselling. The type of counselling varies widely, for instance, a comprehensive review found that the telephone has been used in the delivery of psychotherapy, psycho-education, case management, support and education interventions, as well as help lines (Gotay and Bottomley, 1998). *Helplines* provide information and counselling, are usually accessible by a toll-free number and oriented towards problem-solving (Bucher & Houts, 1999; Marcus et al., 2002).

Evaluation research indicates that one-on-one telephone interventions are used by patients to discuss issues similar to those they would discuss in face

to face counselling sessions, and that counsellors provide essentially the same services. Rainey (1985) conducted a content analysis of 2000 calls to a telephone helpline, and reported that patients discussed issues surrounding their feelings of anxiety, problems with family, and problems with patient-doctor communication. Counsellors provided information, assessed needs, linked patients to community services and provided psychological help.

In another evaluation, Marcus et al. (2002) reported that three-quarters of callers to a one-on-one telephone counselling service called with enquiries for medical information, but by the end of the call, two-thirds asked for and received psychosocial support. In both of these studies, users were predominantly female, white, and highly educated, and the larger proportion of callers were family members or friends compared to patients.

There is scientific evidence that telephone interventions are effective with medical patients (Hornblow, 1986), but surprisingly few strong studies have been conducted with cancer patients. One such study -- a randomized controlled trial conducted by Samarel, Tulman, & Fawcett (2002) – suggests that telephone support may be as effective as face to face support.

In this study, the experimental group received both individual telephone and in-person group support and education focused on symptom and stress management, coping, self-image and sexuality, social functioning and interpersonal communication. One control group received only the telephone intervention while a second control group received a mail out of educational information. Both the experimental and first control groups reported less mood disturbance, less loneliness and higher quality relationships with a significant other compared to the second control group. No group differences were found for cancer-related worry or well being. Two other randomized studies comparing face to face with telephone counselling reported similar results: both interventions improved psychosocial status and there were no differences between telephone and face to face (Sandgren et al 1997; Hagopian and Rubenstein, 1990).

Thus there is reason to be optimistic that individual telephone counselling approaches are effective, but more randomized controlled trials are needed to determine the most effective method, the patient groups with whom the interventions are most effective, and cost effectiveness (Gotay and Bottemley 1998).

Group support

People have participated in cancer support groups for nearly 30 years (Klemm et al., 2003). Using teleconferencing technology in a support group format has all the potential advantages of teleconferencing mentioned previously. However, an added benefit is that the telephone allows individuals who are isolated by factors such as geography or type of cancer to participate

in a group that might not be available otherwise. For example, a prostate cancer patient who lives in a rural area may be able to connect with other patients in a larger urban centre. Similarly, a group of individuals with a relatively specialized condition such as metastatic breast cancer or brain cancer, who are geographically dispersed throughout a province, may be able to meet by way of teleconference.

Evaluative research on the use of teleconference for cancer group support interventions indicates evidence of therapeutic factors. Heiney et al.'s (2003) investigation of a teleconference support group for breast cancer patients found that patients' instillation of hope, altruism, universality, imparting of information, and group cohesion were present in teleconference sessions. Similarly, Rosenfield & Urban (1994) reported that a facilitated intervention enabled patients to share information and experiences with each other. A study described by Colon (1996) reported on a supportive expressive support group that included discussions of feelings, death, isolation and intimacy, and relationships. The program was not formally evaluated, but participants reported feeling comfortable and a sense of continuity.

Church and his colleagues' (Church, Curran, & Solberg, 1999; Curran & Church, 1999) evaluation of a facilitated support group for women with breast cancer in Newfoundland-Labrador provides a current Canadian example of the use of teleconferencing technology in a rural context. The investigated support group utilized teleconference infrastructure from Canada's largest telemedicine network and included participants from 23 communities, many with small populations between 5,000 -10,000 people. Discussion topics included breast cancer detection, management of symptoms and side-effects, treatments, diet and exercise, family support, the aftermath of mastectomy, breast reconstruction, bereavement and death and dying. Curran & Church (1999) reported that the program helped women in rural communities to find support, to feel "not alone", and to share their experiences with others. The majority of women (79%) who responded to a satisfaction reported that the group addressed their needs for social support and information. Women were satisfied with the informal role of the facilitator, comfortable sharing with others, found a sense of intimacy and safeness, and received help from others (Curran & Church, 1999).

Many women also indicated that they were satisfied with the technology. On the other hand, responses from a small number of women indicated that they thought that unfamiliarity with the equipment and the lack of face-to-face contact was a disadvantage. Some women chose to meet face to face with other participants, as a supplement to teleconference contact, if they were living in close proximity.

Bucher and Houts (1999) describe what is perhaps the most innovative and comprehensive psychosocial program delivered by telephone. COPELINE is a helpline that incorporates a bulletin board type system of individual and

group support for family caregivers of cancer patients. The system is designed to provide follow-up support for individuals who have taken a course on family caregiver education that focuses on helping caregivers with problem-solving. Callers use a touch-tone phone to navigate the system, which include sample discussions, a support group, information, and mail. Like an actual bulletin board where users are able to read and respond to others' messages, users of COPELINE are able to listen to and respond by voice to messages left by others. The system incorporates participation of both health care professionals and peers and allows caregivers a way to receive information as well as give and receive emotional support and advice. There are no published data on effectiveness at this time.

3.2 Videoconferencing

Like teleconferencing, videoconferencing involves real-time interaction but includes a visual as well as audio component. At the basic level, videoconferencing involves cameras, monitors, microphones, speakers, software, and a medium for audio and video transmission (Rothchild, 1999). Similar to teleconferencing, videoconferencing has the potential to reduce access barriers caused by geography, transportation, and housebound status (Siden et al., 2001). This technology has the additional benefit of enabling users to communicate using visual cues, which enhances the sense of contact and connectedness (Cukor et al., 1998; cited in Rothchild, 1999). Some barriers to using videoconferencing include cost, acceptance, need for technical support, and ability to ensure privacy and confidentiality (Rothchild, 1999).

Videoconferencing is one of the most extensively used technologies in telehealth programs. A report of 43 telehealth programs in Canada (Deber, Kraetschmer, Dick, & Jennett, 2003) found that the main uses were for clinical, educational (for professionals primarily) and administrative purposes. The report did not discriminate between types of clinical activities and therefore it is not known whether these included psychosocial care. Evaluations of videoconferencing in the context of psychosocial care were not available. However, a recent review of telepsychiatry (Hilty, Marks, Urness, Yellowlees, & Nesbitt, 2004) indicated the existence of 14 telepsychiatry programs in Canada, and noted that clinical applications are varied and include therapy and support interventions.

Hilty et al's review concluded that videoconferencing it has been successful for a variety of clinical and educational purposes, has been well-received, and compares favourably with in-person care (Hilty et al., 2004). Furthermore, access to psychiatric services in rural, suburban, and urban areas has improved. Diagnostic reliability of various psychiatric disorders has been very good and is comparable to in-person care. Hilty et al's review cites a few studies which reported that clinical changes achieved were equivalent to in-

person care and a number of studies that reported patient satisfaction with the service.

For instance, one study of the BC/Yukon telehealth program with psychiatrists found high levels of satisfaction on the parts of both patients and professionals (Center for Telehealth at Mheccu, 2003). Patients were satisfied with the session and found the equipment easy to use. They felt they presented the same information that they would have in person and that the doctor listened to them; they felt supported and encouraged and comfortable interacting with the doctor, and were able to express concerns.

Studies of provider satisfaction have produced mixed results, which may be due to the variable quality of the videoconferencing technology. That is, the ability to communicate well is affected by audio and video quality that in turn is determined by transmission speed. Significant transmission delays impede communication and are particularly frustrating to professionals. Nevertheless, providers agree that videoconferencing allows the building of rapport between provider and patient.

Experimentation with video conferencing for new patient assessments in the diagnostic phase of cancer care shows promise with pilot work conducted at the BC Cancer Agency. In this example, patients participate in a video call, normally in the presence of a doctor and/or nurse in a location close to the patient's home. An oncologist reviews patient records in advance and then discusses care plans with the patient. The doctor and nurse provide additional clarification. Pilot work has indicated patient satisfaction with this assessment and the added advantage of reducing wait time and travel costs. The patients' care can be managed by the family doctor. Future work will incorporate a psychosocial assessment and support with a trained psychosocial specialist.

Despite the promise of videoconferencing, there is great variation in quality of technology which limits clinical utility, and again there is a lack of strong research evidence. As Hilty and his colleagues noted, randomized controlled trials and more research regarding clinical outcomes and cost-effectiveness are needed (Hilty et al., 2004).

3.3 Computer

Computer applications of psychosocial care in oncology include electronic support groups and comprehensive computer systems, such as websites, which provide information and educational resources. These applications may provide a service which is synchronous (interaction occurring in real-time) or asynchronous (interaction is not in real time).

Asynchronous communication includes computer enabled bulletin boards, newsgroups and mailing lists -- each of which handles electronic messages slightly differently, but are alike in that electronic messages may be read and

posted at any time. For example, a computer bulletin board is much like one that would hang on a wall in an office or home: each message is posted to the board and anyone with access to the board may read and respond to messages. Synchronous communication, on the other hand, occurs in real-time. A chat room is synchronous and could be likened to a traditional support group meeting except that it meets electronically rather than face-to-face.

Like the other technologies, computer interventions have advantages and disadvantages (Eysenbach, 2003; Finfgeld, 2000; Penson, Benson, Parles, Chabner, & Lynch, 2002; Sullivan, 2003; Winzelberg et al., 2003). Advantages include independence from geography, transportation, and homebound status barriers. In addition, the computer allows for complete anonymity and thus no cues for stigmatization. There is potential for greater freedom of expression which may be associated with increased self-disclosure, expression of negative emotions, discussion of taboo subjects, honesty, and intimacy. Given the potential population of users, there is also a greater possibility of finding peers, especially for those with rare conditions. For asynchronous communications there are additional advantages: being free from time barriers and therefore being free to think, edit and be more creative with responses, and having control over the degree of involvement. For example, a member of a bulletin board may choose to visit the board once a day or once a month and may choose to post messages or simply to read them.

Identified disadvantages of computer interventions include lack of physical contact and proximity, risk of social isolation, and risk of dissemination of inaccurate information. Although freedom to express negative emotions is seen as an advantage, it can also be a disadvantage when flaming (the hurtful or harmful expression of negative emotions) occurs. Additional disadvantages for asynchronous interventions include large volumes of mail and lack of a facilitator. As well, participation in computer applications requires computer and often Internet access, some degree of computer literacy and language competency.

Electronic support groups

Most computer interventions involving psychosocial support are asynchronous electronic support groups and are unmoderated (Eysenbach, 2003). Like face-to-face support groups, the degree of moderation or facilitation by health care professionals differs among groups. Some electronic support groups are led by a facilitator who sets the topics for discussion whereas others are facilitated only to the extent that supportive and non-hurtful interactions are encouraged. Still other groups are not moderated at all.

As of March 2003, the Association of Cancer Online Resources hosted 235 cancer mailing lists. Content analyses of bulletin board messages indicate

that most messages are based on information and support and sharing of personal experiences, similar to face-to-face interventions (Eysenbach, 2003). A study (Sullivan, 2003) that compared the bulletin board messages of females in an ovarian group and men in a prostate group found that men connected through information-sharing and were heavily influenced by the participation of male physicians whom they had invited to the group. Women, on the other hand, developed an online community of similar others where they had a safe place to talk, a place to build relationships, and a place to share personal stories and help others cope. Another study of asynchronous communication among various cancer lists asked 42 participants (mostly female) to compare the support provided by the list to that provided by a significant face-to-face support person (Turner, Grube, & Meyers, 2001). This study found that both the list and face-to-face supports were perceived to be available for help, but that the importance of the face-to-face support was greater. In addition, the authors found that individuals participated more online when that support was perceived to be high and their face-to-face support was low.

Although relatively little scientific research has been performed, two recent studies indicate that computer interventions can be effective. Winzelberg and his colleagues (2003) report on a study of 72 breast cancer patients who were randomly assigned to either an immediate or wait-list control newsgroup support group facilitated by a mental health professional. The group followed a model of supportive expressive therapy and the facilitator's role involved keeping the discussion on topic and encouraging an atmosphere of support. As with other interventions, participants reported getting support, encouragement, and advice, were able to express feelings, helped others, found their problems were not unique, and developed new friendships. The authors also note technical issues around connectivity and speak of ethical issues around the limits of confidentiality and the role of the moderator. The experimental group showed reduced depression, cancer-related trauma and stress compared to the wait-list controls, with effect sizes comparable to those found in face-to-face groups. No group differences were found for anxiety or coping.

The Wellness Community is a non-profit organization in the United States that provides free psychosocial support and education to cancer patients and their families. The Wellness Community offers the only professionally-led synchronous electronic support groups for cancer patients (Lieberman et al., 2003). Each support group also has its own (asynchronous) newsgroup which is available any time of the day for participants to read meeting transcripts and communicate with each other during the week. Individuals register for participation in electronic support groups on the website, after which their diagnosis is verified with their physician. Support groups are facilitated by therapists who are trained in the Wellness therapeutic model which encourages patients to "become empowered to make active choices in their

recovery, thereby reducing unwanted aloneness, loss of control, and loss of hope” (p. 922).

The Wellness Community conducts both facilitator and participant evaluations of its online programs on a regular basis. Facilitator evaluations include assessments of satisfaction, role, and function while participant evaluations assess satisfaction and clinical outcomes. Lieberman et al. (2003) reported that the intervention reduced depression and pain reactions, and was judged to be helpful by the majority of participants. Members reported that they were able to talk without fear of being judged and shared more than they might have in a face-to-face interaction. On the other hand, some members had difficulty with the speed of incoming messages, and some experienced technical problems as a consequence of slow modems, entry-level computers, and Internet provider timed out sessions.

Comprehensive programs offering support and information

Another computer-based program that is impressive in scope is that developed by Gustafson and colleagues, the Comprehensive Health Enhancement Support System (CHESS). CHESS is a closed, guided system of information and support that includes information tools, analysis tools, and support tools (Gustafson et al., 2002). Information resources include a database of questions and answers, an instant library, a consumer guide, and resource directory. Analysis tools are aimed at helping users think through important issues and include assessments, health tracking, decisions, and action plans. Finally, the support tools include an “Ask an Expert” section, a bulletin board discussion group, personal stories, and a video gallery. The bulletin board has a maximum of 50 participants and is professionally facilitated to ensure supportive communication and monitored for inaccurate or harmful information. CHESS is geared towards people facing a crisis and has been used with different patient groups including HIV-positive patients and extensively with breast cancer patients (Gustafson et al., 2002). The computer system is available through the Internet or as an installable software program and access is gained via a codename and password.

Breast cancer patients who used CHESS experienced improved information and social support and increased participation in health care, and this was especially the case with traditionally underserved populations (Gustafson et al., 2002). Studies of CHESS indicate underserved people (e.g., elderly, African American) use the system as much as more affluent Caucasians but use communication services less frequently and information and analysis services more, which is particularly important for quality of life (Gustafson et al., 2002). For example, women of color (mostly African American) used the discussion group less than Caucasian women and used it to focus specifically on breast cancer issues (as opposed to chatting about day-to-day and interpersonal issues) (McTavish, Pingree, Hawkins, & Gustafson, 2003). A qualitative study of 12 women with breast cancer found the computer support

group to be a unique source of support (emotional and informational) and found that anonymity fostered equalized participation among members. They further found that asynchronous communication was sometimes frustrating but also allowed for more flexibility with respect to schedules and more thoughtful interaction (Shaw, McTavish, Hawkins, Gustafson, & Pingree, 2000). Evidence of the therapeutic components of universality and altruism were also evident as participants noted that they benefited from communication with similar others and from helping others.

In summary, the research literature supports the idea that communication technologies, overall, offer feasible and acceptable means of delivering psychosocial support to cancer patients. However, more research is needed to establish the extent to which they are effective in bringing about specific quality of life outcomes, for whom, under which conditions, and at what cost.

4.0 Results II - Communication Technologies & Psychosocial Care in Canada

The other main objective of the investigation was to assess the current and likely future use of communication technologies for providing psychosocial care to cancer patients in Canada. This was assessed through interviews with key informants located in Canadian Cancer Agencies and other facilities. Agency-based providers of psychosocial care were queried about use in their organization, and the interest and ability to develop and implement future programs utilizing communication technologies. This led to further discussion of the issues and concerns of providers as these are potential barriers to organizational uptake. In addition, informants from several innovative University/research-based programs utilizing communication technology were interviewed, with the aim of being able to describe these programs and the perceived challenges and benefits associated.

In this section, current use and interest are described, and then the concerns and issues are discussed with the intention not only of identifying them, but seeking solutions drawing from both the research and the key informants.

4.1 Current use in cancer organizations and hospitals

Key informants were asked about the technologies currently used to deliver psychosocial care to patients and families. The group of Canadian support providers included eight administrators of hospital or cancer organization programs. Of these 8, 5 reported that teleconferencing was used systematically in their organization, and 3 reported the use of videoconferencing. None of these informants used computer applications as a means of delivering psychosocial services.

With regards to use of teleconferencing, only one informant reported that the telephone was used in the context of group support group. Five informants reported that teleconferencing was used in their programs by counsellors for one-on-one provision of support. Responses suggest that professionals provide telephone counselling on a case-by-case basis, and that some use it every day. This type of service provision was not monitored formally.

Videoconferencing is a relatively new service within cancer care, as reported by key informants – use ranging between one month and a maximum of one year. In Alberta, Manitoba, and Ontario, videoconferencing occurred through an already-established telehealth infrastructure within the provinces. In all provinces, the technology is being used for one-on-one videocounselling. Manitoba has additionally been using videoconferencing for speech-language, dietary, and sexuality counselling, and for support groups. Unfortunately, key informants indicated that evaluation looked only at patient satisfaction, and was either inconsistent or not yet in place.

4.2 Interest in future use of communication technology

All support providers expressed interest in using communication technologies in the future as an aid to improve access to programs. Many articulated the point that communication technologies were valuable as an alternative for patients; that a variety of approaches were needed to assist people. They indicated that many patients and family members have life circumstances and ways of learning and coping that do not 'fit' the normative group support/individual counselling approaches based in the central Cancer Agencies. They articulated that clients should be given the option of choosing the services that they are most comfortable with. Caution was also expressed as informants indicated the need for evidence-based practices.

Informants expressed the view that technologically-aided psychosocial programs be seen as a complement to and not a replacement for face-to-face support. The greatest value of technology was that it could gain patients access to programs that might not otherwise be available (e.g., for individuals living in remote communities). A few informants spoke of the importance of not using technology as an excuse to decrease care in rural communities. In some cases, technology may provide an alternative for individuals receiving face-to-face support. In other cases, technology may serve as a precursor to face-to-face support, as was the case with the Newfoundland-Labrador audio teleconferencing group and the breast cancer bulletin board group initiated by Jon Church. In this case (and others reported in research), a non-face-to-face medium spawned an annual get-together of participants.

Since different key informants had experience with different media, the particular technologies they considered for future implementation differed. The three most common applications mentioned were 1) expansion of websites (e.g., making psycho-educational and skill-based materials available, adding visual components, adding "Ask a professional" components), 2) electronic support groups, and 3) videoconferencing. One key informant who has been using videoconferencing via a telehealth network suggested that he would like to see more portable systems (e.g., palm pilots, web cameras) used in the future so that he could conduct counselling sessions from his office and clients could stay at home, instead of going to the nearest videoconferencing centre.

Key informants identified a number of different populations that needed improved access to psychosocial/supportive care programs, and who they thought would particularly benefit from the implementation of communication technologies.

These included those who:

- ❑ are separated from available face-to-face services by geographic distance such as those in rural or remote communities.
- ❑ face other geographic and travel barriers, not only due to sheer distance, but also due to weather, traffic, road conditions, or cost.
- ❑ are housebound, perhaps because they are too ill to travel or have mobility difficulties, such as the elderly and end-of-life patients.
- ❑ do not have the time to utilize existing programs. These would include those who work or have childcare responsibilities during normal working hours, and who might benefit from evening and weekend programs. Another group that faces time barriers is caregivers who are not able to leave their loved ones.
- ❑ might need specialized programs that are not available otherwise such as metastatic breast cancer or palliative care.
- ❑ tend to be uncomfortable with face-to-face services such as teens, men, those in small communities who might be recognized or stigmatized.
- ❑ are underserved ethnic groups who face cultural and language barriers with traditional services, such as the Aboriginal community or the Chinese community.
- ❑ are of lower socio-economic status and/or literacy.

Thus there is clearly interest by support providers in Canada to develop and implement programs that use communication technologies, and those who could benefit within the Canadian context have been identified. Interestingly, increasing use of the telephone was not raised by the support providers, although patient's report satisfaction and, in the broader medical literature, there is evidence for clinical effectiveness (Hornblow, 1986).

4.3 Psychosocial programs utilizing communication technology

Five key informants not based within Cancer Agencies reported on programs that utilized communication technologies to deliver psychosocial support. These programs are described below:

Teleconference Self Help Support Group

The teleconference support group for breast cancer patients originated by Jon Church, Associate Professor, Terry Fox Research Labs, Memorial University of Newfoundland, has already been discussed. In addition to the use of

teleconferencing, Church has managed a mailing list for breast cancer patients, since 1994. This list is non-facilitated, although Church does participate as a content expert.

As stated earlier, there is research support that the teleconference group is satisfying for participants but there is no data on clinical outcomes. Funding is provided by the Canadian Cancer Society.

Canadian Virtual Hospice

The Canadian Virtual Hospice (<http://www.virtualhospice.ca>) is a newly developed (i.e., less than 6 months since launching) Canadian comprehensive computer system, somewhat analogous to the CHES. It is an interactive network of information and support for those dealing with palliative care situations. Although not specific to end-of-life care for cancer, many of the system's users are dealing with cancer. The key informant indicated that the Hospice is intended as a supplement to, and not a replacement for, the palliative care provided by health care professionals. The website deals with the physical, emotional, and spiritual aspects of end-of-life care. The system contains four different portals depending on whether the user is a patient, family member or friend, health care professional, or volunteer. Users may keep a journal of personal reflections; submit questions to professionals; and access information, frequently asked questions, online support through bulletin board and chat room, and additional resources.

Because it had only been operational for a few months at the time of writing, the Canadian Virtual Hospice did not yet have evaluation data to report. However, plans for program evaluation include usability testing and satisfaction assessments. Funding is provided by numerous granting bodies, both national and within Manitoba.

The Centre for Global eHealth Innovation

The Centre for Global eHealth Innovation is a Canadian organization devoted to helping people, "regardless of who or where they are, maintain the highest levels of health, while making efficient use of health resources" (Centre for Global eHealth Innovation, 2003b). The Centre studies and promotes information communication technologies in the health sector.

One of the Centre's current programs is the *Virtual Clinic* (Centre for Global eHealth Innovation, 2003a). This program is an Internet-based resource that is designed to facilitate the patient-health care provider relationship. Three of the program's components include (a) a virtual coach for patients, a decision tool that helps people prioritize questions for discussion with their health care provider; (b) an Internet clinical communication centre, which allows patient and provider to communicate regarding illness management; and (c) a virtual supportive care centre, an information resource tailored to patient needs. This

is essentially a research program, and the key informant indicated that they have collected evaluation and some clinical outcome data, but it is not available yet. Funding is provided by several research granting agencies.

The Healing Journey

This program, developed by Dr Alastair Cunningham, is a (live) psycho-education program based at the Princess Margaret Hospital, teaching psychological and spiritual practices to promote inner harmony and healing (Cunningham, 2004). Traditionally, users of the program are aided by workbooks and audiotapes. Very recently, the workbook for the first level of the program has become available over the Internet. This level teaches methods of relaxation, thought management, mental imagery, and goal-setting. In addition, Internet resources include a weekly electronic chat room that enables users to obtain support from each other and from Cunningham and his colleagues. The original program has demonstrated clinical outcomes such as reduced depression and anxiety and increased perceptions of control, however, the virtual program is not being evaluated. Initial funding was provided through private and corporate gifts and currently it relies on volunteer assistance.

Cancer Connection

Cancer Connection is a nationally-based peer support program that aims to provide emotional peer support to clients through a telephone relationship. This program matches patients with trained volunteer survivors or caregivers, based on criteria such as age, cancer site, treatment, children, marital status, and sexual orientation. Client satisfaction data is collected but results have not been disseminated to our knowledge. The program is funded by the Canadian Cancer Society.

4.4 Issues and concerns likely to affect organizational uptake

When the research literature and key informant interviews are examined as a whole, it can be seen that communication technologies have great promise as a means of increasing the impact of psychosocial programs by improving access. However, the use of these communication technologies is not unproblematic, particularly with regards to introducing new programs of service. Over the course of this investigation, issues and concerns were raised by both researchers and health providers. These issues and concerns can be viewed as barriers that need to be overcome, or conversely as requirements that need to be in place before programs can be developed and implemented. They need to be addressed on behalf of healthcare organizations and patient and caregiver user groups.

Ideas and solutions to some barriers have been identified in previous research, and the key informants also offered ideas and suggestions. The

main issues and concerns raised are discussed in detail below, as are the ideas and potential solutions.

Funding is inadequate or unstable

Issue: Funding is required in order to implement new programs or augment existing programs. Core funding for psychosocial programs is already stretched, and research funds are time-limited. Where will the money come from?

Introducing new technologies is costly. Any supportive care/ psychosocial program utilizing telecommunications technology requires trained health care professionals, technical support staff and materials – hardware and electronic infrastructure such as coaxial cable or computer servers, adequate bandwidth for audio and picture quality in the case of videoconferencing.

Key informant data indicated that current technologically-aided programs in Canada are funded through various sources including core budgets of organizations, provincial health funding, and research grants. Teleconferencing costs probably pose the least challenge: they are increasingly small and tend to be absorbed by core operating costs of cancer organizations. The cost of infrastructure is more expensive if teleconferencing is going to support large numbers across a wide area. Jon Church's teleconferencing group was able to get started because it received funding from the Canadian Cancer Society.

Videoconferencing programs are much more costly, and depend on existing telehealth networks which are funded by provincial health care funds. Without an already-existing infrastructure for the technology, these programs would not exist. Fortunately national initiatives are in place to expand telehealth (Deber et al., 2003) and so that should serve to facilitate implementation.

Computer-based programs and services pose the greatest challenge at this time because they require the injection of new funds. The cost of supporting software can be substantial, as these programs tend to be highly sophisticated and initial development costs have been high. There are also the costs of training health professionals in their use. On a positive note, with regards to software required to run computer-based applications, programs such as the one used by the Wellness Community are available in the public sector. For comprehensive programs such as CHERS and the Canadian Virtual Hospice, software is custom-designed; however, key informants indicated that plans are to eventually make the programs available to the public so that other organizations may use the technology. Thus it could simply be a matter of time before these programs are available.

In Canada, the computer-based programs that do exist, such as the Canadian Virtual Hospice and those operated through the Centre for Global eHealth

Innovation, receive funding from grants as well as national and regional health monies. These monies are not stable though, and conversations with key informants indicated that there is a need to identify stable core funding once the research functions have been served and the funding is ended.

Key informants offered a number of ideas and solutions for the issue of funding; most were directed to the broader systemic levels while others could be achieved closer to home:

- Urge governments to regard psychosocial care as an integral component of cancer care. Provincial and federal government agencies need to recognize the importance of supportive care when allocating health care dollars. New monies, rather than the re-allocation of existing budgets, would be ideal.
- Develop partnerships with other users of the technology. In this way the costs of the technology, related infrastructure, and support services could be shared, thus reducing the economic burden for any one organization.
- Urge administrators to support training programs for health professionals and technical support staff so that users are knowledgeable and are able to utilize the technology efficiently.
- Consider partnerships with the business community in providing consultation and or hardware to facilitate better access.

Ethical and legal issues

Issue: The use of technology in delivering psychosocial care poses some special ethical and legal concerns involving security, liability, and reimbursement.

Introducing new technologies implies identifying and resolving a whole new set of ethical and legal considerations. Security measures to protect privacy and confidentiality for telephone, video, or computer technology must be addressed in order for health care professionals and clients to be comfortable with its use. For example, an email transmission may not be secure, may be tracked, and may contain identifiable information (Bauer, 2001). Safety and well-being of clients who are distressed and not physically present poses challenges, and security efforts that protect privacy can conflict with ability to intervene when necessary.

Additional ethical and legal issues include those of reimbursement, licensure, and liability (Gustafson, Robinson, Ansley, Adler, & Brennan, 1999; Styra, 2004). Practices such as telephone or email counselling may not be acknowledged in the remuneration of some health care professionals. Reimbursement and licensure may be particularly relevant in those cases

where programs transcend local licensing certifications. In addition, standards of care for technologically-aided support (e.g., email counselling) and the establishment and responsibilities of a clinician-patient relationship may be unclear, which in turn, has implications for liability and malpractice (Bauer, 2001).

Fortunately, these issues have been thought through by researchers, clinicians and practice leaders working in the area, and creative and feasible solutions have been identified. For example, the developers of the CHES program and those responsible for the Wellness Program have developed guidelines to address issues such as dealing with confidentiality when someone exhibits suicidal ideation in the context of the bulletin board. The Canadian Virtual Hospice requires its users to register and accept conditions of use, one of which is that no physician-patient relationship is said to be established within the context of the Hospice.

Another concern often raised by clinicians relates to the interpersonal quality of the clinician-patient relationship. There are concerns about the lack of non-verbal cues available to “read” a patient, that emotional connections may be more difficult to establish, and concern of an increased risk of dehumanizing a patient due to reduced physical contact. Interestingly, these concerns are less often raised by patients who, overall, report being open to and benefiting from distant therapeutic relationships through computer and videolink (Bauer, 2001).

Key informants identified the following measures as necessary steps prior to establishing communication technology-aided programs:

- Develop security measures for privacy and confidentiality that are specific to the type of technologically-aided support.
- Ensure clinical guidelines and standards of care are in place for psychosocial support delivered via technological means.
- Develop resources for training and consultation to potential providers of care. Optimally, they should be developed and made available nationally.

These steps in place would allay ethical concerns. As for the legal issues, a good first step would involve consultation with the Virtual Canadian Hospice as a great deal of legal expertise went into the development of policies for this ‘national resource’.

Equality of access

Issue: The technologies discussed require special equipment and/or services that may not be equally accessible to all interested users.

New technologies can be accessed only by those populations who have the technologies at hand. Lack of access is a social problem that communication technologies have been proposed to ameliorate, however, many traditionally underserved populations are those that do not have access to computers and the Internet or are not able to use them. With particular regard to computer-based applications, attention must be paid to the fact that not all people have access to a computer and/or reliable Internet connections. A concern raised by many of our key informants was whether the use of technology would widen or bridge gaps in access to psychosocial care.

This concern can be addressed in part by examining data. According to Statistics Canada's Survey of Household Spending (Statistics Canada, 2003a), in 2002 nearly all households had a telephone, over 90% had a VCR, about three-quarters had a CD player, and one-third had a DVD player. Nearly two-thirds of Canadian households had a home computer, and just over half had Internet access from home. Although little difference is apparent between rural and urban households with respect to having a telephone or VCR, fewer rural households contain CD players, DVD players, and home computers. Selected data is reproduced in Table 2.

Thus while there are clearly populations who do not have access to high speed internet and thus the supportive services requiring this, telephone access and video machines are nearly universal. Increasingly, even very remote communities are able to access health services through telehealth initiatives.

*Table 2
Percentage of Canadian Households Having Selected Household Equipment in 2002*

<i>Equipment</i>	<i>All households</i>	<i>Rural</i>	<i>Urban</i>
Telephone	98.7	97.8	98.9
VCR	92.1	91.3	92.2
CD player	73.7	67.5	74.9
DVD player	35.8	25.2	37.8
Home computer	63.9	54.0	65.9
Internet use from home	54.3	43.1	56.5
Type of Internet connection			
Regular telephone connection	25.1	37.6	22.6
High speed telephone connection	13.6	2.9	15.7
Cable connection	15.3	2.4	17.8

Note: Data is based on the 10 provinces only.

Note: F indicates data were too unreliable to report.

Source: Survey of Household Spending (Statistics Canada, 2003a)

The concern that remains is that limited access factors tend to correlate, thus compounding the problem for particularly disadvantaged groups. For example, preliminary work with British Columbia's rural women's population indicates that low-income women do not have the resources for a computer or Internet access (Baker, 2003). Aboriginal women believe the Internet to be a valuable tool for information and communication but face economic and geographic barriers to access (Golic, 2003). Communication technologies remain likely to be least accessible to the most marginalized groups.

These concerns lead to the following recommendations:

- Ensure that technology is used as an adjunct to, and not a replacement for, face-to-face supportive care. In this way, as many options as possible may be made available to clients.
- Encourage initiatives to provide public access to needed equipment that is housed in relatively private locations where clients' communications would remain secure (e.g., computer and Internet access in a study room of a public library).

Comfort: Technology and literacy proficiency

Issue: Intended users must feel comfortable with the technology.

The use of new technologies for supportive care requires health providers and patients to be proficient in their use. Several key informants indicated that discomfort with innovative communication technologies on the part of health care providers as well as patients present a barrier to use of the technology. Reluctance may stem from unfamiliarity with equipment. For example, teleconferencing and videoconferencing may feel awkward for some individuals as they are required to speak into a microphone or look into a camera.

In the case of computer technologies a certain degree of computer literacy is needed. Since some of these computer technologies require people to use the written word to communicate, language literacy and typing skills are also issues to consider. Thus literacy, education, and physical disability may all be barriers (Eng et al., 1998). In the case of computer bulletin boards or online support groups, people may be afraid their typing is not proficient enough. Certainly those individuals who do not possess minimal typing proficiency or literacy probably are not using the medium.

Some of these concerns have proven not to be an issue. For instance, unfamiliarity with teleconferencing and videoconferencing are lessened through gradual exposure to the technology (Ho, 2000). Key informant responses indicate that users are not inhibited by literacy issues and realize that the clarity of presentation of ideas is more important. While there has been a common perception that elderly clients would not be familiar with

computer technology, one program found that contracted training services for seniors was never needed (M. Golant, personal communication, April 7, 2004). Studies indicate that underserved populations can use the technology when access and training is provided (Eng et al., 1998).

Solutions that address these concerns are:

- Have an initial orientation to the technology and/or an initial face-to-face or telephone contact prior to using the technology.
- Provide training to users, especially health professionals, to increase familiarity with the technology. Experience with the technology will also introduce users to potential technological difficulties and provide opportunities to deal with these problems. Users may also see the value of using technology through training and experience.

Client awareness and acceptability

Issue: Intended users may not know about the potential of technology to enhance and enable their supportive/ psychosocial care.

Improving access to psychosocial care requires that potential clients are both aware of the services and aware of their value. In the case of live services, many groups benefit from psychosocial care but have members who do not utilize them for reasons of fear and stigma, and lack of awareness that such programs and services exist. Given that this is an issue for 'live care', it is likely to be an issue in technologically-delivered care.

There are a number of ways to address the concern of client awareness and accessibility. Mass media, making outcalls, physician referrals, and different outreach strategies have all been suggested as means to improve awareness (Marcus et al., 2002), and appear to be practical and effective. Personal or phone contacts may be most effective. For instance, one of our key informants whose organization screens for distress found that follow up phone contacts providing patients with information about available services were well received, and that half of these individuals indicate interest. In a study of the feasibility of providing online support to breast cancer patients, 45% of participants agreed to take part in the treatment when approached directly, and this method was much more successful than other recruitment strategies such as posters, television, radio, and web advertisements (Owen, Klapow, Roth, Nabell, & Tucker, 2004).

Patients are perhaps more ready and willing to embrace technology than health providers. Studies indicate that using technology to deliver supportive care is acceptable to clients: Gotay and Bottomley (1998) reported from one study that three-quarters of the 115 breast and prostate cancer patients surveyed would be likely to call or be called by a telephone counselling service, and in another study of 30 breast cancer patients, most indicated that

telephone counselling would be acceptable. Monnier, Laken, and Carter (2002) surveyed 319 men and women in the waiting rooms of a South Carolina cancer centre and found that 55% would be “likely” or “very likely” to use an online support group. Forty-nine percent said they would use the Internet for coping assistance and 31% would utilize online conversations with a psychologist.

There are population differences in how acceptable technological means are to patients. Monnier et al (2002) found that ethnic minorities, less educated, and older individuals were less likely to have used or have knowledge of the Internet; however, no differences were found for urban/rural or patient/caregiver groups. Owen et al. (2004) found interest in participating in electronic support groups higher in younger women, but not associated with distance from clinic, education, income, time since diagnosis, or stage of disease. Furthermore, nearly two-thirds of women in this sample thought that Internet-based therapy would be equally or more likely to result in improved physical and mental health outcomes compared to face-to-face therapy.

Thus the following is suggested:

- Clients need to be made aware of all options available to them with regards to receiving supportive care. This means that available technologically-aided support programs need to be appropriately marketed. The most effective strategy may be for health professionals to introduce programs to potential clients.

5.0 Recommendations

This investigation has shown that communication technologies indeed have great promise for improving access to psychosocial/supportive care. Enough research has been conducted to be confident that patients are willing to utilize technology and that they do derive benefit. There is interest on the part of support providers and a good deal of infrastructure already in place. Much can be done now to move forward!

5.1 Recommendations for Organizational Uptake

As noted by others, the implementation and use of technology to improve access to supportive care requires the collaboration of health professionals, health organizations, policy makers, and researchers to make changes to clinical practices and policies (Ho, Chockalingam, Best, & Walsh, 2003; Ho et al., 2004). The technology must appeal to its users, health professionals need to see the value in using it, and administrators must support development and implementation (Ho et al., 2004). In other words, increased collaboration, knowledge and a commitment to funding are necessary.

In the remainder of this section, some recommendations are offered. These can be seen as actions steps at different levels for bringing Cancer organizations closer to implementing technology enabled programs of support.

Teleconferencing

Of the three technologies discussed in this report, teleconferencing has the greatest potential for immediate uptake. Nearly everyone has a telephone and thus access to the required hardware is a problem for a very small number of individuals. In this respect, the telephone offers a more equitable option for providing psychosocial care to clients. In addition, cancer organizations and hospitals are likely to have the capacity to teleconference. The available research on satisfaction with teleconferencing indicates a favourable response by users and evaluation studies show promise in effecting therapeutic and clinical outcomes.

Recommendations:

- Support providers should be encouraged to offer telephone support to clients who live at a distance. They should become knowledgeable about the evidence for clinical effectiveness, and receive brief training on group facilitation, in order that they are comfortable and competent with the modality.

- Standards of practice and guidelines should be followed, and additional standards developed for telephone contact (e.g., for privacy and confidentiality) if not already in place.
- Organizations should develop guidelines to encourage the use of teleconferencing. This includes appropriate remuneration.

Videoconferencing

Videoconferencing is another technology-enabled option that in many cases is underutilized and ready for uptake. That is, in many Provinces the infrastructure is set up, with sites across the province that are telehealth-capable. Videoconferencing is cost-effective when it is “piggybacked” on the infrastructure of telehealth networks in Canada. The provincial cancer organizations in Alberta, Manitoba, and Ontario are references for existing psychosocial programs using videoconferencing, and in BC, the infrastructure is in place. The challenge is increasing utilization.

Recommendations:

- Develop partnerships with other organizations/disease site programs that use or would use videoconferencing technology (e.g., general psychiatry).
- Increase comfort with the technology by training health professionals so that they can become familiar with looking into the camera, speaking into the microphone, etc. and potential operating problems.
- Encourage administrators to facilitate use of videoconferencing by offering support staff and training.
- Develop a better understanding of uptake and accessibility issues that are preventing implementation and usage.

Computer

Computer applications have great potential for impact in cancer care although it is the medium which is the least developed with respect to ethical standards, practice guidelines as well as readiness for implementation.

The model operated by the Wellness Community for real-time electronic support groups, for instance, shows great promise as a means of connecting hard to reach populations who might not normally have access to supportive care interventions (Golant 2003). There is also potential to apply other therapeutic models to the computer format. For instance, therapy groups using a supportive Expressive approach could be piloted with hard to reach populations and delivered via the internet.

Comprehensive programs such as CHES and the Canadian Virtual Hospice are enticing because they are multi-featured systems of information and support – in essence a one-stop shop. With respect to psychosocial care, clients have the opportunity to ask a professional/expert about individual questions and concerns and may have access to a real-time electronic support group and 24-hour access to a bulletin board support group. However, these comprehensive programs were very costly to develop. Until further study on the benefits of the programs becomes available and until the software becomes available to the public or substantial funding is available, comprehensive computer applications will not be available for immediate uptake.

The lack of equitable access to computers presents a dilemma in that computer-based applications will not be available to many users. However this situation is likely to change within a relatively short time, as statistics indicate that computers and Internet access in the home are rapidly increasing (Statistics Canada, 2003b). However, whether the digital divide will narrow for those underserved communities such as rural, low-income, and Aboriginal populations remains a question.

Recommendations for computer-aided supportive care:

- Expand websites. One suggestion made by a number of key informants was to use websites more effectively. For example, available audiotapes, videotapes, and compact discs could be made available through the Internet on the websites of cancer organizations such as the BC Cancer Agency. A search of the BCCA library catalogue indicates that many resources in these mediums exist for patients and their families for relaxation and coping. Key informants from across the country indicated similar resources in their organizations. Due to copyright permission guidelines, those materials that were produced in-house should provide a starting place for appropriate materials to place on the website.
- Involve health professionals in bulletin boards. Although bulletin boards are primarily unmoderated, they do provide an avenue for health care professionals to provide psychosocial care. Two patient advocates said that they would like to see professionals involved as members of the bulletin board to provide content expertise, but not to lead or moderate the discussions. Potential roles of facilitators requires further study.
- Encourage policy makers to provide public access to computers and the Internet and to develop the infrastructure for high-speed connections, especially in remote communities.
- Develop a national approach for therapeutic interventions and support to insure an economy of scale.

- Develop a national funding mechanism to insure the provision of computer based support under the auspices of a national body such as the Canadian Association of Provincial Cancer Agencies in conjunction with the Canadian Cancer Society and the Canadian Strategy for Cancer Control.
- A potential resource is the availability of computers and staff support from local libraries. Partnerships with library resources need to be explored and pilot work applied to improve patient access to this technology.

5.2 Recommendations for Future Research and Collaboration

The appeal and value of technology-enabled supportive care for many stakeholders depends, in part, on available research evidence which supports the efficacy and feasibility of the applications. The findings of the current report indicate that teleconferencing, videoconferencing, and computer applications have promise in effecting positive outcomes. However, further research needs to be conducted in these areas. Evidence-based practice is needed if health care providers are to adopt new programs.

Conduct high quality clinical trials

With respect to teleconferencing, Gotay and Bottomley (1998) in their review of telephone interventions for cancer patients concluded that much more research is needed on how best to deliver a telephone intervention, (type of counsellor, type of intervention, duration, structure, objective), for whom it is most effective (geographical isolation, stage of disease, those who refuse other services, minority ethnic groups), and the cost of these interventions (concomitant use of medications, health care services, community services).

No available studies were found on the effectiveness of videoconferencing in delivering psychosocial care to cancer patients and their families. Research on those Canadian sites that are already using the videoconference technology should be performed.

The areas noted above for further research in teleconferencing also apply to computer applications. Adequate evaluation to this point has not occurred and efforts to promote an evidence-based approach with respect to safety, quality, and efficacy are needed and may be aided by standardized evaluation instruments (Robinson, Patrick, & T. R. Eng, 1998). However work is underway: the Wellness Community is currently studying transcripts of their online support and face-to-face support groups to delineate the unique aspects of each type of group (e.g., with respect to content and role of facilitators) and the mechanisms for successful outcomes.

Use diverse research samples of participants

Much of the research in the area of technology-enabled supportive care in oncology has been on women and breast cancer patients. More work needs to be done on other groups and especially those groups who are the targets of improved access. For example, before any program is implemented, focus groups with underserved populations should be carried out to obtain their views about the program. Evaluation studies also need to ensure inclusion of a diverse group of participants in their samples.

Develop an integrated approach

Many of the studies cited in this report are isolated ones. The studies often involve a single centre and/or relatively small samples. A more integrated approach to research would be beneficial. For example, interested researchers across Canada could form a working group to discuss research initiatives focussed specifically on improving access to supportive care using technology. Collaboration of ideas would lead to collaborative research efforts to develop and carry out multi-centre clinical trials. This would serve to expand both the breadth and depth of research and would enable the recruitment of diverse samples of individuals.

Maximize available resources

The literature review and environment scan revealed that Canada already contains a great deal of human and infrastructural capital to develop technology enabled supportive care interventions for cancer care. Future research in this area needs to draw upon existing technical expertise, organizational capacity for health professional training, and potential of telecommunication infrastructure to support psychosocial research and care interventions.

For the purpose of providing operational funding for research, a process needs to be developed in conjunction with the Canadian Strategy for Cancer Control to encourage funding bodies to target knowledge generation in supportive care in cancer. An example is to work with the Canadian Institutes for Health Research and the National Cancer Institute of Canada to develop special research initiatives such as request for applications (RFA's) to advance research knowledge for supportive care and technology.

Canadian leadership

Leadership is needed to advance research and program development in the application of telecommunications technology in supportive care. A number of formal networks have been established in Canada, notably the Sociobehavioural Cancer Research Network (SCRN) that has the capacity to take a leadership or mentoring role.

Establishment of a national task group or network to advance the application of technology in supportive care should occur. A group will require the affiliation with national organizations such as the Canadian Association of Provincial Cancer Agencies, the Canadian Cancer Society and the Canadian Strategy for Cancer Control. These efforts will help sustain advances in the area and reduce the potential for overlap and duplication of efforts.

Collaboration and partnerships

Policy makers, researchers and health professionals need to think creatively in the formation of new partnerships that will facilitate the development of clinical interventions and research studies for supportive oncology care. Ground work from various sectors has set the foundation for the development of telehealth infrastructure and demonstrated many innovative uses of telecommunication technology to meet supportive care needs. Future research in this area by cancer care stakeholders needs to draw upon what has already been done and what is already known. Opportunities exist to partner with stakeholders outside the Canadian cancer care sphere, such as public libraries, industry, regional hospitals, and international researchers, in order to pilot and test models of technology enabled supportive care in Canada.

5.0 Conclusion

Boldness has power, genius and magic in it... Begin it now. Goethe

In order to assist more cancer patients and their families to improved quality of life, it is essential that we identify innovative and cost efficient ways of delivering knowledge, support and psychological tools. It is essential that our reach extend beyond reasonable travel times of cancer centers, where the majority of oncology-specific psychosocial knowledge and services are located. It is essential that we develop formats that work for people who do not want, or are unable, to participate in our now-conventional forms of delivering service. Communication technologies can enable us to make enormous progress on challenges that relate to limited access.

The conventional view, at this time, is that communication technologies are tools to support and augment existing services and not replacements for face-to-face contact. However, because of their flexibility and convenience we may discover that for many people, they offer a more feasible and useful adjunct to medical care than do existing services. We may find that very high quality programs can be developed and made available to large numbers, and to regions and populations not currently receiving any psychosocial tools. We may discover that patients and families are empowered in new ways, and that we can be facilitative in ways that are both cost efficient and more powerful. At this point in history we simply do not know the potential of communication technologies, but we know enough to move forward into action now.

Afterward

Some work is currently underway. Relationships have already been established with recognized leaders in the area (i.e. Mitch Golant, the research head of the Wellness Community and Janine Geise-Davis, researcher at Stanford) and representatives of cancer support programs in Canada at a meeting funded by CSCC held in Vancouver, at BCCA in June 2004. Discussions with participants indicated an interest in working with the Wellness Community as a model to adapt and develop as a Canada wide approach. A proposal will be underway to pursue this possibility of collaboration and innovation. We view this as an opportunity to engage stakeholders, develop national supportive care resources, conduct a clinical study and contribute to the practical and clinical understanding of technology enabled supportive care with immediate implications for knowledge translation. Other initiatives and opportunities for collaboration in communication technologies are being actively sought out. For further information, contact rdoll@bccancer.bc.ca or jstephen@bccancer.bc.ca.

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Appendix A

Key informant interview questions for support providers

Information about Interviewee:

1. Organization?
2. Position?
3. When started position?
4. Academic background?
5. Years experience as a professional in oncology?

Current technology:

6. Do you have any P/S services that are provided via technological means?
 - a. Audiotape
 - b. Videotape/CD-ROM/DVD
 - c. Teleconferencing
 - d. Videoconferencing
 - e. Computer
 - f. Other, specify
7. How are these services funded (i.e., Are these avenues built into the infrastructure of the organization or are they funded externally)?
8. Describe the barriers you see in providing P/S care via technology?
9. What recommendations or suggestions do you have on how to overcome these barriers?
10. Do you keep track of patients and families that use the (technologically-based) services?
11. Has the program/service been formally evaluated?
12. Are there specific populations or patient groups in your community that you feel particularly benefit from your technologically-based programs?
13. What is your view about how consumers view the appropriateness of these health technology approaches (i.e., acceptability, relevance, feasibility)?
14. What types of capabilities are needed to implement various health technologies (may be more specific about type of technology)?
 - a. Hardware
 - b. Software
 - c. Human resources
 - d. Cost
 - e. Other

Future technology:

15. What are your suggestions about how to improve access to P/S care via technological means?
16. What is your current interest in implementing P/S programs via technological means?

17. What capacity do you have to carry out a program? Would you have the resources (human, financial, technical, etc.) to implement a new program?
18. Who would be the targets of these technologies (tumour groups, demographics)? In other words, who would particularly benefit?
19. What issues do you see as possible barriers to improving access via technology (e.g., ethical, technical)?

Other:

20. Are there any documents or reports that you could provide me that would help me understand your attempts to increase access to P/S services via technological means?
21. Suggestions for other key informants?