Evaluation of CancerChatCanada: a program of online support for Canadians affected by cancer


ABSTRACT

Background

Professional-led cancer support groups can improve quality of life and address unmet needs, but most Canadians affected by cancer do not have access to or do not make use of cancer support groups. A collaborative interdisciplinary team developed, operated, and evaluated Internet-based, professional-led, live-chat support groups (osg) for cancer patients, caregivers, and survivors across Canada.

Objective

Our study aimed to report participant and participation characteristics in the pan-Canadian initiative known as CancerChatCanada, and to understand participant perspectives about the quality of communication and professional facilitation, overall satisfaction, and psychosocial benefits and outcomes.

Methods

Participants in osg provided informed consent. Participant and participation characteristics were gathered from program data collection tools and are described using frequencies, means, and chi-squares. Patient, survivor, and caregiver perspectives were derived from 102 telephone interviews conducted after osg completion and subjected to a directed qualitative content analysis.

Results

The 55 professional-led osg enrolled 351 participants from 9 provinces. More than half the participants came from rural or semirural areas, and more than 84% had no received previous cancer support. The attendance rate was 75%, the dropout rate was 26%, and 80% of participants were satisfied or very satisfied. The convenience and privacy of osgs were benefits. Meaningful communication about important and difficult topics, kinship and bonding with others, and improved mood and self-care were perceived outcomes.

Conclusions

Our results demonstrate that this collaborative initiative was successful in increasing reach and access, and that pan-Canadian, professional-led osgs provide psychosocial benefit to underserved and burdened cancer patients, survivors, and family caregivers.

KEY WORDS

Cancer, Internet, psychosocial, online support, professional-led, confidentiality, program evaluation

1. INTRODUCTION

Canadian cancer patients report multiple challenges and losses that give rise to emotional distress, unmet psychosocial needs, and a desire for professional help through specialist services. Family members caring for cancer patients also experience challenges and psychological morbidity that worsens as patient quality of life deteriorates. Survivors face challenges and concerns about preventing recurrence, treatment-related symptoms, staying healthy, and physical disability and deformity; and they similarly express a desire for expert and peer interactions.

Support groups are important adjuncts in the cancer care continuum and have been shown to help alleviate psychosocial symptoms related to cancer and improve quality of life. Specific benefits include increased knowledge and decreased mood disturbance, trauma symptoms, anxiety, and pain. However, many people are unable to access cancer support groups because of social barriers, lack of specialist services in their area, and work or caregiving responsibilities. Geographic location of residence is a primary contributor to inequity of
access to cancer services\textsuperscript{18}, such that patients and caregivers in rural areas experience quality of life poorer than that of their urban counterparts\textsuperscript{19–22}. Psychosocial distress is compounded by a lack of specialized psychosocial services\textsuperscript{15,17}. About 30\% of Canadians are rural-dwelling, highlighting the importance of developing relevant interventions that can be reached by all Canadians affected by cancer.

Canada has both a relatively small population spread over a vast geographic area and a well-developed telecommunications network. Internet communication is an emerging and important component of Canadian health care reform and a priority innovation\textsuperscript{23,24}. The Internet offers a promising avenue that specialized health care professionals can use to reach underserved populations\textsuperscript{25–27}.

2. BACKGROUND

In 2006, an inter-professional group from 7 Canadian cancer centres in 5 provinces came together to discuss the potential of the Internet for delivering support services to cancer patients who faced challenges accessing psychosocial care. We envisioned a collaborative, national, Internet-based service that would meet the same standards of practice and patient safety as those in our centre-based programs. We consulted with quality control, safety, risk management, and technology personnel at our respective cancer centres to establish that we could offer an Internet-based service in accordance with institutional guidelines, and that organizational insurance would protect licensed professionals in the event of a patient complaint or lawsuit. The project was approved by the research ethics boards at all our partnering academic institutions. Based on published guidelines and models\textsuperscript{28–30}, we developed a comprehensive set of protocols, procedures, and practices to conduct online support groups (OSGS). In 2007, using the secure Web site of U.S. colleagues (the Cancer Support Community), we began operating and studying OSGS.

Our study was guided by several broad questions:

- Can we provide a collaborative, pan-Canadian psychosocial service?
- Can we reach Canadians affected by cancer, including highly burdened and underserved people?
- Does this service appear to meet the psychosocial needs of patients in meaningful and satisfying ways?

In 2010, we developed and launched a fully-Canadian Web-based program branded as CancerChatCanada (http://cancerchatcanada.ca/). Central operations and accountability reside with the Provincial Psychosocial Oncology Program, BC Cancer Agency, where the project lead and 2 staff members oversee and coordinate the service. Clinical and research leadership and group facilitation are distributed among team members of partnering cancer centres in British Columbia, Alberta, Manitoba, Ontario, and Nova Scotia.

3. PROGRAM DESCRIPTION

3.1 Intervention

CancerChatCanada offers professional-led live-chat support groups for cancer patients, survivors, and family members caring for patients. These text-only groups take place in real time, providing a private and experientially-immediate venue for small groups of participants to form close bonds based on shared cancer-related experiences. The facilitators help to guide and focus the discussions toward therapeutic aims, which include enhanced knowledge and confidence with respect to coping; provision and receipt of social support; improved mood and reduced isolation. Weekly, 90-minute groups are held at a scheduled time, with the same facilitator and participants, for 10 or 12 weeks.

3.2 Facilitator Training and Supervision

Facilitators are staff members of partnering cancer centres, with a minimum of 4 years’ experience in oncology. All hold masters or doctorate qualifications in the fields of social work, psychology, clinical counselling, or nursing. Facilitators take part in a minimum of 10 weeks of training to learn facilitation techniques for text-only groups, as first developed by the Cancer Support Community in the United States\textsuperscript{31,32}. They also adapt cognitive behavioral and supportive expressive approaches for the online chat groups they lead. Facilitators attend peer-supervision sessions and complete weekly clinical notes, which are monitored for attendance and technical issues by staff at the central office.

3.3 Participant Privacy, Safety, and Data Security

Unlike most other support Web sites, CancerChatCanada is a “gated community,” offering secure group discussions that take place in private chat rooms, shared only by screened members. Participant identity is confirmed by the enrollment coordinators, and support needs and mental health history are assessed. Persons with an untreated or severe mental health condition are referred to local services. We also gather emergency contact information and the name and telephone number of the participant’s primary physician. The Web site uses encryption and offers the same level of data security as financial institutions do. Lastly, an informed consent process educates participants about protecting their passwords and refraining from using personal identifiers while in the online chat room.
3.4 Participant Enrollment Procedure

Once approved, participants receive an e-mail message from the enrolment coordinator with instructions and login information. The coordinator is available by e-mail or telephone to assist participants with Web site or other technical concerns. The facilitator sends a welcome note that clarifies group objectives and offers tips for communicating effectively online. Once a group begins, the enrolment coordinator sends weekly reminders and remains as a contact in the event of questions or concerns, or as a communicator of absences to the facilitator.

Usually, members take part in a single group lasting 10 weeks, which is the extent of their involvement. Occasionally, members decide to maintain connections with others through e-mail or other Web-based social tools, or to join a second online group.

4. PROGRAM EVALUATION

The objectives of the program evaluation were to determine if

- the national collaborative succeeded at providing an online service to Canadians affected by cancer, including those who are underserved and highly burdened; and
- whether the service appeared to be providing psychosocial benefits to group participants.

Because professional-led live-chat OSGs are innovative, we used a discovery-oriented methodology that would yield descriptive narratives suitable for deriving a grounded understanding of this form of psychosocial support. Additionally, we gathered data that would enable us to make decisions about matters related to future development and quality improvement of the program. We chose “interpretative description” (ID) as the analytic approach because it is well-suited for studying clinical problems and has the goal of informing action. As with other qualitative methods, ID primarily uses an inductive process to derive qualitative themes from the data. However, consistent with its pragmatic goals, ID often includes the flexible use of other analytic procedures. Within ID, we used directed analysis (that is, analysis guided by the theory or research question, or both) and summative analysis (counting and ranking). Our goals were to understand the perspectives of participants on the quality of OSG communication and the contribution of the professional facilitator. We also wanted to assess the overall satisfaction of the participants with OSGs and their perspectives on beneficial outcomes they might have experienced related to information gains, behavioral changes, or emotional changes, so as to determine whether OSGs appeared to yield psychosocial benefits.

4.1 Data Collection

We used a relational database program (Microsoft Access 2003: Microsoft Corporation, Redmond, WA, U.S.A.) to store all enrolment enquiry and participant data. Transcripts of chat room sessions (which are automatically generated by the technical platform) and facilitator clinical notes were stored and used to track attendance and to maintain clinical supervision. We conducted 20- to 45-minute semi-structured telephone interviews with a subsample of 102 participants within 6–8 weeks of group completion.

Initially, every participant was invited to complete an interview about their experience in the online support group. As data were analyzed and saturation was achieved, further interviews were conducted with a purposive sample—in this case, participants from populations that were underrepresented in the analysis to that point. Participants were asked to describe their experience in the OSG, with probes specific to understanding the ability to communicate meaningfully through the technology, helpful or hindering behaviors from the facilitator, and any benefit achieved with respect to learning or to behavioral or emotional change. Interviewees included participants with various cancers at various stages, family caregivers, and participants having high and low attendance in the groups. Interview notes were taken during and immediately after the interviews.

4.2 Data Analysis

Simple descriptive analyses (frequencies, means) were calculated to characterize participation, participants, and attendance. Chi-square tests were used to test differences in attendance, dropout rate, and satisfaction between participant types (caregivers, patients, rural and young survivors).

Four members of the research team participated in a directed qualitative content analysis. In the first phase, all interview material relevant to the 3 study questions was extracted. A second-level coding frame incorporating a priori criteria was developed to sort and rank responses as representing “high” satisfaction or benefit, “moderate” satisfaction or benefit, and “dissatisfaction” or “no benefit” (Table 1). All the interview data was coded by 3 raters using the satisfaction frame. The raters then met to resolve discrepancies by returning to the original overall interviews, reviewing the coding frame, and reaching consensus.

5. RESULTS

5.1 Participation

5.1.1 Enrolment

Between January 2008 and December 2011, enquiries were tracked from 9 provinces or territories. Of 681
people who contacted the office, 472 were cancer patients (69%), and 209 were family caregivers (31%). Of those 681 people, 351 (52%) enrolled in either a patient or a caregiver group. Among non-enrollees, 15% were waiting for a suitable time, 15% were lost to follow-up, 13% decided to decline enrolment, and 5% were referred elsewhere (Figure 1). During the study period, 55 online support groups were held. Of those groups, 19 were for breast cancer survivors; 19, for caregivers; and 17, for patients with a mixture of diagnoses. Some groups were conducted within 1 province ($n = 24$) or 2 provinces ($n = 11$); others were pan-Canadian ($n = 20$).

### 5.1.2 Participants

Most participants (Table 11) were women (88%), diagnosed with breast cancer (52%), middle-aged (mean: 51 years), with at least some college education (55%). Fewer than half were currently employed (41%). Approximately 44% ($n = 155$) were from cities or towns with a population of at least 100,000; 55% ($n = 194$) were from small towns and rural areas. About one quarter (26%) reported either a current mental health condition or a history of such. Relatively few (16%) had previously participated in a professional-led cancer support group.

<table>
<thead>
<tr>
<th>Rating</th>
<th>Criterion</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>High satisfaction or benefit</strong></td>
<td>Communication</td>
<td>Enthusiastic or multiple comments about meaningful communication; online technology described as preferable, or as aiding communication and expression; technology was never a hindrance and communication was very satisfying.</td>
</tr>
<tr>
<td></td>
<td>Facilitator involvement</td>
<td>Enthusiastic appreciation for facilitator, with 3 or more examples of specific helpful behaviors, or outcomes or results attributed to facilitator involvement.</td>
</tr>
<tr>
<td></td>
<td>Overall experience and outcomes</td>
<td>Explicit statement that the experience was “better than expected,” with examples of positive outcomes. Describes 3 or more specific positive outcomes (learning or emotional change) attributed to group experience; or single powerful outcome and enthusiasm indicating high level of engagement.</td>
</tr>
<tr>
<td><strong>Moderate satisfaction or benefit</strong></td>
<td>Communication</td>
<td>Experience was positive overall, but account lacks descriptive detail indicating high engagement; balances advantages and strengths with limitations of communicating through text, within context of a meaningful communication experience.</td>
</tr>
<tr>
<td></td>
<td>Facilitator involvement</td>
<td>Overall positive appraisal, but fewer than 3 specific behaviors or outcomes; positive appraisal with a single qualifying comment that reduces enthusiasm.</td>
</tr>
<tr>
<td></td>
<td>Overall experience and outcomes</td>
<td>Explicit statement that “expectations were met,” and statement of benefit or value or positive outcome is identified. Suggestion is that experience was enjoyable, but did not result in specific therapeutic outcomes or changes.</td>
</tr>
<tr>
<td><strong>Low satisfaction or benefit</strong></td>
<td>Communication</td>
<td>Describes negative communication experience: either limitations or frustrations with technology, or with ability to express or to feel understood by others.</td>
</tr>
<tr>
<td></td>
<td>Facilitator involvement</td>
<td>Makes a complaint about the facilitator, or single positive statement is outweighed by negative comments, or indicates perception that facilitator was not needed.</td>
</tr>
<tr>
<td></td>
<td>Overall experience and outcomes</td>
<td>Responses suggest participant was seeking something different or was expecting more from participation. The rater infers from overall comments that the participant would not elect to join an online (live chat) support group again.</td>
</tr>
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55 online support groups were held. Of those groups, 19 were for breast cancer survivors; 19, for caregivers; and 17, for patients with a mixture of diagnoses. Some groups were conducted within 1 province ($n = 24$) or 2 provinces ($n = 11$); others were pan-Canadian ($n = 20$).

**Figure 1** Consort Diagram of CancerChatCanada (ccc) program from January 2008 to December 2011. ccc = online (live chat) support group.
5.1.3 Attendance
Weekly attendance in group sessions ranged around 75%. Approximately 44% (150 participants) attended more than 80% of their group sessions; 25% (n = 84) attended between 60% and 80% of sessions. Twelve percent of participants (n = 42) attended about half the sessions (40%–60%), and 19% (n = 63) attended fewer than 40% (Figure 2). Attendance did not differ significantly between the groups.

The dropout rate was 26%; specifically, 67 participants dropped out after a mean of 3.5 sessions, and 24 attended no sessions. The dropout rate was significantly higher for caregivers (31.6%) and patients (32.6%) than for survivors (13.5%). Some participants could not be reached to obtain their reasons for leaving (n = 20), but among those who could be contacted, scheduling or work-related issues (n = 16), illness recurrence (n = 11), or dissatisfaction with the group (n = 8) were mentioned. Among caregivers, the reason most often cited for dropping out was the death of the loved one being cared for; among patients, illness or recurrence and scheduling were the most frequently mentioned reasons for dropping out.
5.2 Satisfaction or Benefit of Professional-Led Live-Chat OSGs

Of the 102 interviews conducted, 36 were with young and 26 with rural breast cancer survivors; 20 were with patients from mixed-diagnosis groups; and 20 were with family caregivers. The directed qualitative content analysis yielded understanding in 3 areas relevant to interpreting satisfaction and psychosocial benefit of professionally-facilitated OSGs. There were no significant differences between the 4 participant groups in those areas.

5.2.1 Communication Through Technology

Most participants were rated as having high or moderately high satisfaction and psychosocial benefit from their experience communicating in the live-chat OSGs. Among the 102 interviewees, 44% were rated as “very satisfied” or having “high benefit”; 45%, as “moderately satisfied” or having “moderate benefit”; and 11%, as “dissatisfied” or having “no benefit” (Figure 3).

Communicating with others in a live-chat group was experienced by many participants as challenging for the first 1 or 2 sessions; however, the convenience of being able to access support from home outweighed those challenges. Most participants quickly adapted and came to appreciate the unique characteristics of facilitated text-only discussion. The privacy and semi-anonymity of being online were highly valued and enabled participants to speak more openly than they might have done in a face-to-face setting. Writing instead of talking was found to be helpful, because it provided time for reflection and to organize thoughts. In addition, writing did not get in the way of emotional expression in the way that talking might (for example, crying is possible while typing, but not while talking). Importantly, most participants found that they were able to communicate openly and easily with others, to form social bonds, to feel understood and cared about, and to be able to give support and encouragement to others. Many participants were surprised by the depth of their feelings of kinship and bonding with the members in their online support group.

Participants who were rated as “dissatisfied” and having “no benefit” had difficulties expressing themselves or did not feel understood by others. Sometimes—but not always—dissatisfaction was a result of technology “glitches” or a pace of discussion that was either too rapid or too slow.

5.2.2 Contribution of Professional Facilitator

The presence of a professional facilitator was seen by most participants to add value to the OSG discussions, with 69% of responses rated as indicating “high” satisfaction or benefit; 22%, “moderate” satisfaction or benefit; and only 9%, “dissatisfaction” or “low benefit” (Figure 3).

For most participants, the presence of the professional facilitator was seen to be very important. Facilitators were described as providing direction and depth to the chat, steering and suggesting topics, deepening conversation, maintaining discussion focus, offering insights, and ensuring that important topics were covered that might otherwise be overlooked. Facilitators were perceived to have anticipated important issues, summarized discussions, helped members to open up emotionally, showed warmth and understanding, and helped members to understand each other better. Interviewees described facilitators as having helped the group become comfortable with the technology and also as having been a “safety net” during times of emotional upset, someone who helped members in crisis.

Occasionally, a facilitator was perceived to be too quiet and not to be contributing enough to the conversation, leading to a sense that he or she was “unknown” or was not necessary to the group.

5.2.3 Overall Psychosocial Benefit and Outcomes

Participating in an OSG was perceived by most participants to be beneficial: 39% were rated as having
“high” satisfaction or psychosocial benefit; 40%, as having “moderate” satisfaction or psychosocial benefit; and 21%, as having “low” satisfaction or psychosocial benefit (Figure 3).

Participants rated as having “moderate” or “high” satisfaction and benefit experienced changes in mood and behavior as a result of sharing their experiences and learning how others managed similar challenges. They felt relief and a sense of being “normal again,” knowing that they were not alone. Many participants described gaining knowledge about cancer, learning practical tips and new ideas or resources to help with challenges, and learning specific coping strategies. They described feeling stronger and more hopeful about the future, having gained insights or a new perspective about their cancer experiences. Some described taking better care of themselves by improving lifestyle habits, or in the case of caregivers, by making time for their own needs. Oftentimes, interviewees noticed improvements in mood—feeling less angry, depressed, or anxious and more relaxed, confident, and optimistic.

Participants who were rated as having “low” satisfaction and benefit described not feeling emotionally connected or “joined” to others in their group, or feeling unheard, or missing face-to-face contact. Others who did not gain benefit had been seeking more or different information specific to their cancer experience.

6. DISCUSSION

A collaborative group developed, operated, and evaluated an innovative and pan-Canadian service that assisted Canadians affected by cancer. The launch and operation of the service, the participation rates and ability to reach underserved, burdened Canadians, and the reported satisfaction and benefits demonstrate that this initiative was successful in achieving its original goals.

A significant strength of the initiative is that it increased access to professional support for people who were experiencing burden and who, for reasons of geography, work, or caregiver responsibilities, and disease- or treatment-related symptoms, would otherwise not have had access to a psychosocial service. This study demonstrates that the convenience and privacy of online support made a profound difference, increasing patient, survivor, and caregiver access to a psychosocial service.

Another important finding of the study is that professional-led live-chat OSGs provided psychosocial benefits by enabling meaningful communication and the formation of social bonds. Although these groups did not suit all users or meet all psychosocial needs, most participants appeared to gain some or many of the well-documented benefits of participation in support groups for medical patients. That finding challenges a belief held by many health care professionals that Internet-based social relationships are inherently superficial, tenuous, and lacking commitment. Participation rates in online groups vary and can be low, but participation rates in our OSGs were comparable or better than have been reported for other online group interventions and for other face-to-face group interventions.

Several converging factors may have contributed to the relatively high level of social bonding observed. First, the presence of a professional facilitator helped to deepen and focus the discussions, helped members to understand each other better, and created safety for discussing difficult topics. In OSGs, professional moderators (compared with peer-only participation) appear to stimulate higher levels of member engagement and to encourage open discussion of difficult topics. Second, the synchronous (that is, real-time) nature of the OSG resulted in greater immediacy, which is thought to be more interpersonally gratifying. Compared with interventions that offer asynchronous-alone communication, those offering both synchronous and asynchronous communication yield stronger outcomes. These two factors may have contributed to the relatively high participation reported here compared with participation in other OSG studies, which are infrequently professional-led or synchronous. Third, it has been observed that the privacy and semi-anonymity of online groups encourage people to feel less restrained and to say things that they might not volunteer in face-to-face social situations, including support groups. The OSGs may have offered an opportunity for participants to benefit from a “benign disinhibition” effect that could have contributed to their efforts of working through and resolving problems. In Western societies, people affected by cancer have few opportunities to share difficulties, express strong emotion, and be supported while doing so. Thus, it may be that this particular professional-led and synchronous OSG modality offered an optimal social context for this important form of human communication to occur.

A limitation of our study is that the method does not allow for an inference of treatment efficacy or an extrapolation of rates of satisfaction. Controlled trials are needed to test OSG efficacy, and survey methods would be better suited to estimating population rates of satisfaction. However, the method was suited to this early phase of enquiry and its exploratory and pragmatic objectives. Criterion-derived satisfaction scores are less vulnerable to the “thank-you effect”, allowing us to gain an understanding that was grounded in participant experiences and perspectives. Furthermore, the knowledge gained from this method is informing program improvements such as refinements.
to facilitator training and better matching of participant needs.

7. CONCLUSIONS

Many people affected by cancer do not have access to cancer-related support. The demand for Internet-based professional services that can be accessed by people in need—no matter where they live, and at various times of the day and evening—will continue to grow. The present initiative demonstrates that a national collaborative program can be operated in accordance with accepted professional standards and carried out safely and ethically. A lack of reports of harm, and overall high levels of participant satisfaction and benefit, suggest that professional-led osccs represent a potentially valuable option for many people affected by cancer. Since 2010, CancerChatCanada has moved from a project to a program. Currently, our partnerships are being strengthened and expanded to further increase access to underserved burdened populations, with the intention that CancerChatCanada become a permanent resource for Canadians affected by cancer.

8. ACKNOWLEDGMENTS

Without the support of a great number of people across Canada, as well as their openness to embrace innovation, this project would not have come to fruition. Richard Doll and Margaret Fitch had the vision and dedication to initiate and nurture this novel national project. Irene Nicoll and Lee Fairclough provided strategic assistance. Leadership within BC Cancer Agency, Tom Baker Cancer Centre, Cross Cancer Institute, CancerCare Manitoba, Sunnybrook Odette Cancer Centre, and Capital Health/QEI Health Sciences Centre were willing to extend beyond regional boundaries and dedicate resources to a national service. Lastly, many staff at the BC Cancer Agency central office worked tirelessly over 5 years to continuously improve the program and to ensure the best possible experience for cancer patients, survivors, and family caregivers. The project was funded by the Canadian Partnership Against Cancer; the Canadian Breast Cancer Foundation, British Columbia and Prairies chapters; and the Canadian Institutes for Health Research.

9. CONFLICT OF INTEREST DISCLOSURES

The authors of this paper have no financial conflicts of interest to disclose.

10. REFERENCES


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