

Workshop:

“Creating a Community for Knowledge Exchange and Capacity Building in Psychosocial Cancer Care”

May 9 – 10, 2008
Halifax, Nova Scotia

REPORT

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Funders:

Canadian Institute of Health Research (CIHR)
Canadian Partnership Against Cancer (CPAC)
CAPO/ACOP (in-kind support)



CAPO
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March 2009

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EXECUTIVE SUMMARY

This workshop was attended by 33 stakeholders with backgrounds in psychosocial cancer care including health care professionals, health researchers, and representatives from Canadian cancer Community Based Organizations (CBOs). The major goals of the workshop were to foster ongoing working relationships between attendees and further develop a community of practice dedicated to providing high-quality psychosocial support for all Canadians affected by cancer. The workshop focused on the primary task arising out of the 2007 workshop, which was to create a portal/clearinghouse to facilitate information-sharing amongst these stakeholders.

Overall, the participants in this workshop identified the personal and organizational knowledge, skills, and resources they had to offer as members of an online psychosocial oncology community of practice (CoP), as well as the resources and support they hoped to obtain from the community. Participants identified specific characteristics they wanted to see in the website, emphasizing the need for a platform that facilitates interaction, collaboration, learning, and sharing. Inundation of information, disconnect with the medical community, as well as lack of awareness, access and resources, were identified as significant barriers in the development of the CoP.

BACKGROUND

Why This Initiative is Needed Now: The psychosocial context of individuals with cancer and their families

While each person's cancer journey is individual ¹, the diagnosis and treatment of cancer can be stressful events capable of profound and far-reaching effects. Distress is common and can be high, and even disabling, with effects continuing well beyond diagnosis and treatment ¹. Not only must individuals deal with the physical effects of the illness and its treatment, but also with any resulting emotional, spiritual, psychological, and social effects. Beyond the requirement for medical care, attention to psychosocial needs such as reassurance, a sense of comfort and personal control, positive self-esteem, the ability to cope, finding meaning and purpose in life, and information to assist decision-making and to help quell confusion, anxiety and fear¹ is required.

Increasing recognition is being paid to this aspect of care. There is budding evidence for the relationship between psychosocial interventions and enhanced quality of life, and increased survival potential ¹. Meeting the medical needs of cancer patients is essential. However, the psychosocial needs of both patients and their supporters often are not addressed by the conventional medical system, and conversely are increasingly recognized and frequently met by CBOs. There is little published information on how psychosocial needs are being met and limited means to share information among the following "pillars" of psychosocial care: CAPO/psychosocial health professionals, researchers, CBOs, and the conventional medical system.

Project History

2006

This project developed out of a meeting held during the 2006 annual CAPO conference. At this meeting, representatives from 11 CBOs met with CAPO representatives to discuss how CAPO could support them. These founding organizations were: the Canadian Breast Cancer network, The Canadian Cancer Society, the Colorectal Cancer Association of Canada, Lung Cancer Canada, the Leukemia and Lymphoma Society of Canada, the National Ovarian Cancer Association, Ovarian Cancer Canada, Wellspring, RealTime Cancer, Willow Breast Cancer Support Canada, and Hope and Cope. The consensus from this first meeting was the need to develop:

- 1) mechanisms to share information (electronic resources, workshops and training sessions)
- 2) consistent standards (e.g.: reviewing and approving educational materials, developing a standardized curriculum for volunteers)
- 3) processes for research collaboration and knowledge translation (e.g.: implementing research findings on a practical level).

2007

The first step in developing these tools was to carry out a study of the knowledge exchange (KE) practices and barriers to KE within Canadian psychosocial cancer CBOs. Thirteen CBOs were interviewed. The interviews were transcribed and the major themes regarding KE were extracted using qualitative research methodology. Findings from this survey were reported at the workshop in Winnipeg in May 2007, again during the annual CAPO conference. Overall, the participants in this workshop clearly identified a need for a partnership that would link all those providing psychosocial cancer care in a variety of ways. The partnership would have a clear structure, with a vision and a set of achievable goals. It would be allied with the Canadian Association of Psychosocial Oncology (CAPO) and would accomplish two broad goals:

- 1) it would support partners in developing the best possible Knowledge Exchange (KE) strategies and
- 2) those KE strategies would open channels for streamlining of services to survivors and their family members, for sharing expertise in the delivery of programs, and for mutual involvement in research. The project would itself include an evaluation and a strategy for sharing findings beyond the partners.

Early in the 2007 workshop, participants were asked to consider developing a new name for the knowledge exchange project. Suggestions were posted and a vote confirmed our name to be: “Canadian Psychosocial Oncology Partners” (CPOP).

A community of practice (CoP) model seemed to best fill the gaps identified during the 2006 meeting and 2007 workshop. See the report on the 2007 workshop for more details.

THE 2008 WORKSHOP

The aims of the 2008 workshop were to:

- Bring together key stakeholder groups in psychosocial cancer care to further develop the vision of seamless integrated care and to foster ongoing working relationships
- Identify:
 - a. The resources participants have to offer an online psychosocial oncology CoP
 - b. The resources participants want/need from an online psychosocial oncology CoP
 - c. The factors that would keep participants and their organizations involved
 - d. Effective communication tools for the community
 - e. Barriers and gaps the community must overcome in developing a CoP
 - f. Specific functions participants want to see in the website
- Develop a sense of how to market the online psychosocial oncology CoP

PARTICIPANTS:

The event was attended by 33 key participants with backgrounds in psychosocial cancer care including health care professionals, health researchers, and representatives from Canadian cancer CBOs.

ACTIVITIES:

The workshop began on Friday evening. The project leads provided overviews of the concept of knowledge exchange and approaches to building a community of practice. Short talks were given by project partners from CPAC, CAPO, and the Canadian Cancer Society to “set the stage” for the work to be done.

On Saturday morning, Lynne introduced the work with a brief overview of knowledge exchange and communities of practice. She presented models of KE and CoP, emphasizing a collaborative process and focusing on what information should be shared with which audience using which strategies.

Next, Dr. Cameron Norman from the Dalla Lana School of Public Health Sciences at the University of Toronto gave a keynote speech. His talk focused on building CoPs, how CoPs differ from other knowledge creation, transfer, and learning approaches, and the opportunities that CoPs can provide in fostering knowledge development and exchange. Dr. Norman used examples from his work with the Web Assisted Tobacco Intervention (WATI) CoP to demonstrate the challenges of developing a community for information sharing.

The rest of Saturday was taken up by of a series of small group activities. Each task required participants to identify the personal and organizational barriers and facilitators to creating a successful online community of practice in psychosocial oncology. They were asked to identify what they personally had to offer an online community of practice in psychosocial oncology, what they wanted to get out of participating in such a community, the factors that would keep them involved, specific functions and tools they wanted to see in the website, as well as barriers or gaps that the group would need to overcome in order to successfully develop and maintain an online community for researchers, practitioners, and community-based organizations. Finally, participants considered the tools and strategies needed to market the community to others.

Responses from the small group goal-setting exercise were sorted across the groups, summarizing common themes. Groups identified some clear barriers to the success of the community. Grouping responses from the small group work revealed eight key themes. For the most part, we have used the actual words of participants to give depth to each theme.

OUTCOMES:

1. What participants have to offer an online psychosocial cancer community: Specific resources, skills and experience:

a) Personal resources, skills, and experience:

- *Experience with the cancer journey* – survivor, supporter and caregiver perspectives
- *Clinical knowledge and experience* – palliative care, rehabilitation, nursing, public health, social work, social sciences, pediatric oncology, family-centred care, young adults with cancer, quality assurance, complementary medicine

- *Community experience* – teaching, patient education, establishing standards-based platform for community-based psychosocial care
- *Connections* – across cancer research, practice, advocacy and CBO arenas, interdisciplinary, multidisciplinary relationships
- *Business knowledge and skills* – organization start-up, managing non-profits, customer relations, board development, managing and training volunteers, small business owner expertise, marketing skills, leveraging funding for non-profits
- *Research skills* – methodology, writing grants, academic publications, program evaluation, setting up research teams
- *Personal attitudes* – enthusiasm, ideas, and the ability to “see the big picture”, commitment to cancer services, commitment to professional development, desire to “see things through”, solution-focused

b) Organizational resources, skills, and experience:

- *Success stories* – models for successful integrated cancer care services
- *Training and development resources* – volunteer training
- *Connections and networks* – National and global linkages to the cancer community, political connections, networking for patients, families, and survivors, young adult networks
- *Business knowledge and experience* – training and development resources, fundraising experience,
- *Resources* – research, publications, reports, guidelines, articles, patient education tools, websites and webcasting, distance education resources
- *Structure* – to bring community together

2. What participants want/need from others:

- *Resources* – academic and non-academic articles, reports, regional and national resources on psychosocial cancer care, best practice guidelines and standards, standardized curricula for volunteers
- *Access* – to referral programs (regional and national), politicians and decision-makers, family physicians, and government/institution based research and needs assessment programs
- *Advance agendas* – importance of addressing psychosocial needs, cancer in adolescents and young adults,
- *Support* – for new and up-and-coming organizations, financial sustainability,
- *Connections* – inter and multidisciplinary, with other organizations,
- *Tools* – for marketing and messaging through the media, staff training
- *Opportunities* – to share research results, to raise public awareness, to learn about other disciplines, to meet face-to-face, to be recognized, to interact with other CBOs and mentor / be mentored
- *Buy-in* – from health care practitioners
- *Advocacy* – social, political
- *Funding* – opportunities, training in grant writing, for sustainability

3. What would keep participants personally involved in the community?

- *Research* – expanding and enhancing the psychosocial cancer knowledge base, research from across the country
- *Characteristics of the website* – easy to use, easy to access, ability to network, ability to communicate on a one-to-one basis, organized, personal touch
- *Characteristics of the content* – current/up-to-date information, multiple tools, one-stop-shopping, credit for intellectual property, language accessible, relevant to personal “to-do list”
- *Characteristics of the community* – setting achievable goals, achieving small successes, active network, collaboration, give and take, sharing, mentorship, collegial communication, mutual benefit, respect
- *Opportunities* – to interact and connect with others, to spread the grassroots word, to grow and learn
- *Marketing* – branding of the community by creating a CBO brand

4. What would keep organizations involved in the community?

- *Funding* – information about funding opportunities, links to funding, funding development
- *Benefits* - to organization goals, to organization mission statement, builds organizational capacity, to patients directly
- *Characteristics of content* – accessible, credible, reflective of the full spectrum of psychosocial oncology
- *Characteristics of the website* – up-to-date, “living” not archives, affordable (money and time), credible, coordinated with other efforts in psychosocial oncology
- *Characteristics of the community* – democratic, wide range in scope (local, national, international), broad-based, holistic
- *Opportunities* – to profile organizations, to develop partnerships, to access and link with researchers, to be recognized

5. Effective communication tools for our community:

- *Personal tools* – connections, establishing relationships
- *Collaborative tools* – discussion forums, links to the community, listserv with opportunities to connect one-on-one, links to researchers and research
- *Research tools* – information, data, findings,
- *Social networking tools* – Facebook
- *Information sharing tools* – newsletters, updates
- *Learning / training tools* – online courses
- *Meeting tools* – teleconferencing, videoconferencing, Go2meeting.com, Skype, using U-Tube to archive teleconferences, webinars, annual meeting (need human connection)

6. The gaps/barriers we need to overcome:

- *Individual barriers* – inundation of information and emails, lack of time
- *Disconnect with the medical community* – between CBOs and medical community, MDs not trained to work as a team in psychosocial care, difficulty engaging other healthcare professionals
- *Awareness* – importance of psychosocial care, lack of awareness of opportunities

- *Access* – permitting co-workers on the site, access to technology (i.e. web cameras), time zones, working in isolation
- *Resources* – understaffing, lack of equipment, lack of time, lack of funding, marketing skills

7. What is needed on the website:

a) Functions:

- *Barter/trade function* – “I am looking for...” or “I want to research...” or “I can offer”
- *Incentives to participate* – benefits to getting involved
- *News function* – opportunities, news, organization profiles, upcoming events, conferences
- *Bulletin board function* – where users can post information, questions, responses
- *Virtual Library* – cross-linked, books and resources of interest
- *Email* – @cpop.ca email address
- *Search function* – easy to use, find what you’re looking for, specific (not hidden)
- *Wiki function* – to facilitate collaboration, ability to filter through search
- *Archive function* – archived events (i.e. podcast)
- *Ranking function* – to rate/evaluate resources, post comments, “vote with your feet”, quality control

b) Characteristics:

- *Updating* – constantly displaying new information, reports, publications, self-updating,
- *Accountability* – who will maintain this? Who will make sure it’s secure? Who will make sure users can access what they need?
- *Creating Connections* – ability to interact, create partnerships
- *Other* – mimicking real life virtually, reflective of the energy of the community, simple, easy to navigate, individualized homepage, privacy settings

c) Content:

- *Research* – articles, findings, reports, evaluations, CPOP members who are researchers, disease sites, young adults
- *Resource lists* – specific resources with links to organizations
- *Educational tools* – online resources and training tools, volunteer training
- *Job opportunities* – among CPOP members but also larger psychosocial oncology cancer community
- *Program information* – services offered by different organizations
- *Toolkit section* – templates

8. Marketing strategies:

- *Work within the community* – engage existing networks, build on what is already available, post links on other websites, get support/buy-in from current members, snowball (identify who isn’t represented and invite them to join), invite policy makers, engage academic researchers, highlight relevancy for different groups

- *Raising awareness* – among other organizations/communities, encourage collaborative research, professional links, send-to-a-friend feature
- *Marketing* – branding, developing a recognizable logo, social marketing, “Google optimize”, involve the medical community, fundraising, link with provincial organizations and universities offering training in psychosocial oncology, publicize early successes, manage public release, public service announcements

CONCLUSION

Overall, it was evident that the community has a wealth of personal and organizational resources, skills, and experience to offer an online psychosocial oncology community of practice. These included clinical knowledge and expertise, experience with all facets of the cancer community, connections across the practice, policy, CBO and volunteer sectors, research skills, business and entrepreneurial knowledge, as well as personal experience with the cancer journey. Participants want access to resources, support, and opportunities for collaboration from the community, as well as the opportunity to advance the agenda of their organization.

In terms of the factors that would keep participants and their organizations involved in the community, participants identified characteristics of the website, its content, and overall community. Opportunities to interact, collaborate, learn, and share were most frequently discussed. Participants saw online collaboration and communication tools as particularly relevant to the community. They emphasized that social networking platforms (e.g. Facebook) and videoconferencing would be particularly useful because they allow users to maintain a sense of personal or human connection with others. Inundation of information, a disconnect with the medical community, and lack of awareness, access and resources, were identified as significant barriers in the development of the CoP.

EVALUATION of the WORKSHOP

All participants were asked to complete a questionnaire evaluating their experience at the workshop. Because of time commitments, not every participant was able to attend the whole workshop. Of the 33 participants, 22 returned evaluations. Participants were asked to respond to three questions. The first question asked participants to rank their experience of the entire workshop on a 10 point scale, 10 being “most helpful” and 0 being “least helpful”. For the 22 participants that returned their evaluation form, the average score for this question was 8.25. All responses ranged from 7 to 10, with the exception of one 3.

Participants were then asked to provide general comments about the workshop, identify the best thing they took away from the workshop, and the single best thing that organizers could do for the next year’s event. Almost all of the overall comments were positive and participants appeared to feel that they had benefited from the opportunity to take part in the workshop. Some of the comments were:

General comments:

“Really enjoyed hearing the CBO presentations and being able to present our information. Benefited greatly from group sessions”

“I liked the practicality!”

“Excellent opportunity to network and learn about other CBOs and professionals involved in cancer care across Canada”

“Great opportunity for networking”

The best things participants will take away with them:

“Confidence that this initiative will move forward”

“Great opportunity for networking”

“The commitment to cancer care – the focus”

“I come away with access to information and support provided by like-minded organizations. Invaluable!”

What organizers can do for the 2009 workshop to build this community:

“Sometimes that activities were a little unclear in terms of what we were supposed to be focusing on”

“Recruit other CBOs and more researchers to come on board”

“Stay in touch – send monthly updates as the progress of CPOP activities and plans, even if nothing much has happened in that month”

“CBO seminar was GREAT – but please try not to overlap with CAPO (extra day?)”

“Create a plan – a whole plan. It is great to have the website funding but what happens once its developed? We really need a plan of action, perhaps a business plan, that takes us from here t the development of the website and other tools for sustainability and long term direction and management.”

NEXT STEPS

Lynne Robinson from Dalhousie University and Mary Jane Esplen from CAPO applied for and successfully obtained funding from the Canadian Partnership Against Cancer (CPAC) to create a website that came out of the workshop recommendations. This funding was used to build the website, an online psychosocial oncology community of practice for information sharing. Watch your inbox for the official website launch notice!

LIST OF ACRONYMS

CAPO	Canadian Association of Psychosocial Oncology
CBO	community based organization (new term for NGO)
CoP	community of practice
CPAC	Canadian Partnership Against Cancer
CPOP	Canadian Psychosocial Oncology Partners
KE	knowledge exchange
KT	knowledge transfer

Note:

This report is a brief summary of the key workshop presentations and workshop feedback. More detailed information on knowledge exchange, communities of practice and capacity building and the event, including PowerPoint presentations, more comprehensive background information, and a copy of the report on the 2007 CBO survey can be requested through Lynne Robinson.

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REFERENCE

1. Supportive_Care/_Cancer_Rehabilitation_Workgroup. Canadian Strategy for Cancer Control: Supportive Care/Cancer Rehabilitation Workgroup Final Report. Available at: <http://209.217.127.72/csc/pd/finalsupportiveJan2002.PDF>. Accessed June 1, 2006.