Internship Report:
Health Informatics in Psychosocial Oncology

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Acknowledgements and Endorsements

This report has been written by me and has not received any previous academic credit at this or any other institution.

I would like to thank Dr. Rob Rutledge for providing the opportunity to work with him on projects so aligned with my personal interests and passion. Additionally, I would like to thank both Dr. Rutledge and Dr. Lynne Robinson for being wonderfully enthusiastic mentors and allowing me the opportunity to learn from their extensive experience in the field of psychosocial oncology.

Celeste Latter

Executive Summary

This report provides a brief account of the author's internship and details a proposed process for strengthening the provision of psychosocial care, information, and support for cancer patients and their families.

The internship was conducted under the supervision of Dr. Rob Rutledge, a Radiation Oncologist at the Nova Scotia Cancer Centre and Assistant Professor in the Department of Radiation Oncology, Faculty of Medicine, Dalhousie University. Work was carried out on four projects: literature searches for evidence-based information, a consumer health project, Skills for Healing retreats, and a proposal entitled "Creating a Community for Knowledge Exchange and Capacity Building in Psychosocial Cancer Care: Facilitating Collaboration Between NGOs, Professionals, and Researchers". The internship provided the opportunity to apply information and skills learned throughout the Health Informatics program. Health informatics principles, concepts, and values were integral to all aspects of the work of the internship.

A significant component of the work for this internship involved the development of a proposal intended to benefit cancer patients and their families by enhancing psychosocial care. Unfortunately, the psychosocial needs of patients and their families are not being met in a consistent or comprehensive manner. The reality is that there is a lack of integration, communication, and collaboration between key stakeholders in psychosocial cancer care and no mechanism to facilitate enhancement in these areas. The creation of a community for knowledge exchange and capacity building to foster a network with consistent processes for knowledge exchange, and increased opportunities for knowledge sharing and supportive collaboration, is recommended. As stakeholders learn from the perspectives and expertise that each brings to the community, the capacity to create higher quality programs and services in psychosocial cancer care, reducing gaps, will ultimately benefit patients and their families.

There are four key elements in the proposed process: 1), a survey of NGOs to determine their needs and current practices; 2), a conference to bring together representatives from NGOs as well as the professional and research communities; 3), the development of a (n) action plan(s); and 4), the development of a plan for sustainability.

Initial information gathering suggests that that there may be a role for technology in this proposed community. Many organizations are utilizing clearinghouses and on-line communities to house and share health-related information and resources. These sites can serve as potential models for consideration. However, the existence and format of a community for knowledge exchange and capacity building in psychosocial cancer care is a matter to be decided by those attending the proposed conference and their respective groups. More information is required before any solutions and plans can be developed.

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Introduction

The purpose of this report is twofold; 1), to provide a brief account of the author's internship including its primary components and tasks and 2), to detail a proposed process for strengthening the provision of psychosocial care, information, and support for cancer patients and their families. Internship details are presented first, followed by the proposal. The report concludes with an analysis of the internship's relevance to the field of Health Informatics.

Internship

Location

This internship was conducted under the supervision of Dr. Rob Rutledge, a Radiation Oncologist at the Nova Scotia Cancer Centre and Assistant Professor in the Department of Radiation Oncology, Faculty of Medicine, Dalhousie University. Dr. Rutledge is an active researcher and lecturer with particular interest in health promotion and the psychosocial aspects of cancer care. He is also a Board Member of the Canadian Association of Psychosocial Oncology [CAPO] and the lead organizer of the Skills for Healing weekend retreats for cancer patients and their families.

Description

A combination of team and independent work was required. Responsibility was assigned for tasks associated with four main projects. These projects, and their primary tasks, are briefly described below. An approximation of the percentage of time allocated to each project is included.

Proposal (65%)

<u>Project Description</u>

A proposal outlining a process to facilitate collaboration and ongoing dialogue between CAPO and other key partners central to the psychosocial care of cancer patients and their families was developed. Further details about this proposal are contained in the second part of this report.

<u>Primary Tasks</u>

- served as a member of a core team to develop a process and research strategy
- gathered relevant background documentation and information through literature and Internet searches and liaisons with community resource people
- wrote, revised, and refined the proposal based on ongoing team discussion and feedback; prepared other documents related to the proposal (e.g., summary documents for partners)

- identified potential funding opportunities and assisted with writing funding proposals
- developed spreadsheets to assist budget and project management
- assisted in the operationalization of the proposed process (e.g., conference planning, the development of questions for interviews with NGOs)

Literature Searches (15%)

Project Description

Literature searches for evidence-based information were conducted.

Primary Tasks

- searched for, and abstracted, randomized controlled trials showing better outcomes in breast cancer, (e.g., exercise, diet, weight, sleep, meditation/relaxation, support groups), for use at a conference
- located randomized controlled trials regarding aspects of psychosocial oncology from a provided reference list

Consumer Health Project (10%)

Project Description

A theoretical foundation upon which to develop a DVD or web-based programming containing education and skills-based information for those with cancer and their caregivers was initiated.

Primary Tasks

- conducted literature searches for evidence-based information (e.g., cost benefit of psychospiritual interventions, evidence that web-based programming improves the quality of life of cancer patients, most effective programming, proof that people can be taught skills over the Web**)**
- developed a plan for the development, prototyping, and evaluation of a potential product

Skills for Healing Retreat (10%)

Project Description

Skills for Healing retreats are a psychosocial resource offered to cancer patients and their families. Retreat preparation and organization is both labour and detail intensive. Beginning with the retreat in November, participants will have the opportunity to participate in research assessing the long-term effects of retreat participation.

Primary Tasks

- created a Retreat planning timeline and checklist to assist with project management
- obtained information for promotional materials and updated mailing lists
- assisted in editing the ethics proposal regarding the aforementioned research

Proposal

Background

A significant component of the work for this internship involved the development of a proposal that ultimately aims to benefit cancer patients and their families by enhancing psychosocial care. (The term “families” in this context encompasses all those in a close supporting role to the patient.) CAPO defines psychosocial oncology as “a specialty in cancer care concerned with understanding and treating the social, psychological, emotional, spiritual, quality-of-life and functional aspects of cancer, from prevention through bereavement. It is a whole-person approach to cancer care that addresses a range of very human needs that can improve quality of life for people affected by cancer” [1].

The plan outlined in the proposal evolved from a general plan to a more specific plan through the efforts of a small team consisting of the author, a Health Informatics intern with experience working and partnering with not-for-profit organizations and NGOs, Dr. Rutledge, whose work and interests were outlined earlier, and Dr. Lynne Robinson, a Dalhousie professor and colleague of Dr. Rutledge with interest and experience in psychosocial oncology and research.

A draft proposal, intended for distribution to potential partners, was produced. Excerpts from the proposal are utilized in this report along with supporting documentation collected during its development. This information will serve as the foundation for analysis and a subsequent discussion of further considerations.

Creating a Community for Knowledge Exchange and Capacity Building in Psychosocial Cancer Care: Facilitating Collaboration Between NGOs, Professionals, and Researchers

When most people think of cancer care, they think of interactions with the health care system and medical services personnel. Meeting the medical needs of patients is essential, however, cancer patients have needs that go beyond this aspect of care. While each person’s cancer journey is individual, distress is common and can be high, and even disabling, with effects continuing well beyond diagnosis and treatment [2]. Not only must individuals deal with the physical effects of the illness and treatment, but any resulting emotional, spiritual, psychological, and social effects. There is budding evidence for the relationship between psychosocial interventions and enhanced quality of life, and increased survival potential [2].

Unfortunately, comprehensive and consistent means of addressing the psychosocial needs of patients and their families are absent. Adequate priority and resources are lacking within the health care system, for both institutional and community-based programs, to meet the needs of cancer patients [2]. Compounding the issue is the problem of unequal access created by variations across the country in staffing levels, access to relevant disciplines, and programs [2]. The results of a recent patient experience survey [3] underscore the fact that emotional support needs of patients across the country are not well addressed. Patients responding to the relevant portion of the questionnaire indicated that they had not received enough information about emotional and relationship changes, nor had they been linked with an oncology professional to help with their anxiety and fear [3].

Many of the available psychosocial supports are provided by organizations external to the health care system, (i.e., NGOs), often through the efforts of fundraising activities and volunteer commitment. These organizations offer a myriad of services including:

- the provision of information and education;
- the facilitation of peer support through groups, discussion boards, retreats, and mentoring programs;
- the promotion of wellness and enhancement of coping skills through yoga, meditation, and visualization;
- the fostering of emotional expression through creative outlets such as art, music, and journaling; and
- skills training that can be used to assist others (e.g., training volunteers in mentoring programs)

While NGOs play an important role, there are other key “pillars” in the psychosocial care of cancer patients and their families: the conventional medical system and the Canadian Association of Provincial Cancer Agencies [CAPCA], psychosocial professionals, and psychosocial research. Medical and psychosocial professionals constitute an obvious resource for patients. Psychosocial research is instrumental in determining needs and the most effective practices, as well as demonstrating the importance of psychosocial resources.

As depicted in Figure 1, the reality is that the relationships between these pillars of care are linear and sequential. Patients and their families interact primarily with the NGOs and the conventional medical system. The conventional medical system views its primary role as diagnosis and treatment. Clinicians, constrained by time, are prevented from dealing with all of their patients’ psychosocial needs and maintaining currency with the rapidly growing field of psychosocial research and practice. They may be unaware of the services provided by the NGOs. Patients may be referred to psychosocial professionals via the conventional medical system if the need is recognized. Researchers rarely connect with NGOs or patients, resulting in a lack of information about the research needs of NGOs and a lack of access to research participants. Thus, there exists a lack of communication and collaboration between these critical pillars of psychosocial cancer care. Each works in relative isolation from the others and, perhaps, lacks a true understanding of the others’ contributions and needs. Further, no formal mechanism exists to facilitate communication or collaboration and act as a means to tap into the inherent expertise that is available. The result is a fragmented knowledge system functioning without interdependence.

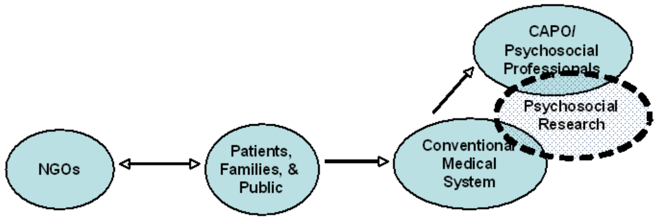


Figure 1 – Lack of integration

Conclusions

The psychosocial aspect of care is important for cancer patients and their families. Unfortunately, these needs are not being met in a consistent or comprehensive manner. There are several pillars or stakeholders key to the provision of psychosocial cancer care, each with their own role to play. The current reality is that there is a lack of integration, communication, and collaboration between these stakeholders and no mechanism to facilitate enhancement in these areas.

Recognizing the degree of services and care currently provided by NGOs, members of the CAPO Board met with representatives from eleven NGOs. Ideas were solicited about what CAPO, an organization of professionals, clinicians, researchers, and educators [4], could do to support the NGOs' work in psychosocial cancer care. Interest was expressed in:

- the development of mechanisms to share information about organizations, publications, and upcoming events;
- professional development;
- the development and upholding of standards (e.g., reviewing and approving educational materials, developing a standardized curriculum for volunteers); and
- enhanced collaboration in research and knowledge translation activities (e.g., assistance with program evaluations and/or research, ensuring resources are evidence-based, and practical application of research findings)

From this initial information gathering, it is clear that information sharing; building capacity; enhancing credibility through the development of standards and use of evidence-based information and research findings; and increased connectivity with researchers and professionals are issues of importance to many NGOs.

Recommendations

The overarching recommendation that serves as the foundation for this proposal is to create a community for knowledge exchange and capacity building.

Inspired by the work of Norman [5], it is envisioned that the current system of psychosocial cancer care can be transformed from a fragmented knowledge system to a connected network with consistent processes for knowledge exchange, thus increasing the opportunities for knowledge sharing and supportive collaboration. Here each pillar becomes a partner, aware of the other partners and their contributions, working as part of an integrated and collaborative system in which knowledge is shared and inherent expertise recognized and utilized (see Figure 2). This knowledge exchange community will together create **seamless psychosocial care, information and support across the cancer journey for patients and families**. As partners learn from the perspectives and expertise that each brings to the community, the capacity to create higher quality programs and services in psychosocial cancer care, reducing gaps, will ultimately benefit patients and their families.

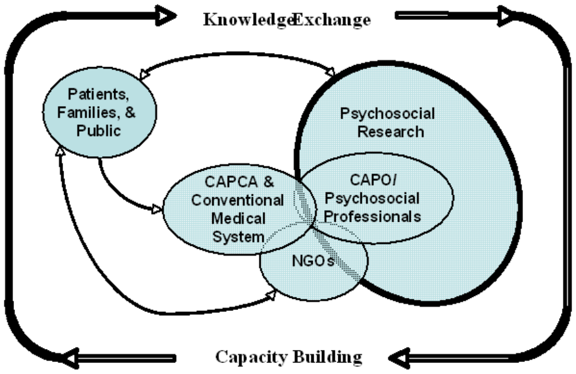


Figure 2 – Integration

Discussion

It should be noted that developing a community to facilitate knowledge exchange and capacity building between the pillars or stakeholders identified above represents a significant change to an established way of working. Therefore, it is extremely important that any solutions are generated by the stakeholders.

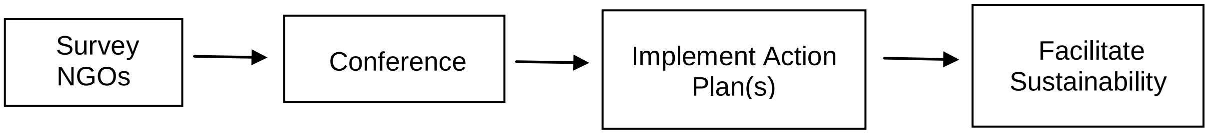
With this mind, a proposal containing a generic process was developed by the author drawing on both previous work experience in which diverse stakeholder groups were brought together to generate collaborative solutions around a public health issue, as well as information on the design of knowledge management solutions presented in HINF 6230: Knowledge Management for Health Informatics [6]. The process included engaging stakeholder groups; collecting information through an environmental scan to further identify the knowledge assets, gaps, and needs of these groups; and the subsequent use of this information to generate and build a sustainable solution that would meet the needs of the stakeholders. This process is contained in Appendix A. From this, the team then developed a more specific process. Details of the more specific process are presented in the following section. The full proposal, intended for distribution to potential partner organizations, is contained in Appendix B.

Proposed Process

There are four key components in the proposed process: 1), a survey of NGOs (this has been selected as a separate step due to the time required to gather information from this number of organizations); 2), a conference; 3) the development and implementation of action plans; and 4), a plan for sustainability.

Steps:

1. **survey** NGOs practices and needs
2. organize and conduct a **conference** for stakeholders in psychosocial cancer care
3. implement **action plan(s)** developed at the conference
4. devolve responsibility for **sustainability**



1. Survey NGOs

Purpose: to collect data from NGOs on their needs and current practices as well as how they evaluate their programs, implement research, and share information

2. Conference

Purpose: to create the foundation for a community of knowledge exchange and capacity building in psychosocial oncology

Objectives:

1. to bring together key stakeholder groups in psychosocial cancer care to develop the vision of seamless integrated care and to foster ongoing working relationships
2. to share NGO survey results and generate an overview of current practices as well as barriers and enablers in knowledge exchange and research between NGOs, psychosocial and medical professionals, and psychosocial researchers
3. to develop (a) sustainable action plan(s) for creating a community for knowledge exchange and capacity building in psychosocial cancer care

4. to generate a set of resources for participants, including funding, to support them in implementing the sustainable action plan(s)

5. to share findings from this conference and outcomes from the action plan(s) at the next annual CAPO conference and through publication

3. Implement Action Plan(s)

Purpose: to further the vision of seamless integrated care developed at the conference by taking active steps to create the community of knowledge exchange and capacity building as developed by conference members

Further detail cannot be provided here as these will be developed at the conference.

4. Facilitate Sustainability

Purpose: to ensure lessons learned and ideas generated at the conference become part of the normal practices of the stakeholders

Conference organizers will be responsible for facilitating the transfer of responsibility to partners who will ensure sustainability.

Several key considerations are accounted for and built into the proposed process. First, members from each of the stakeholder groups will be brought together to identify and share the information needs, assets, practices, etc. of their individual groups. Solutions will be then be generated from the members themselves and not imposed by an outside source.

While the identification of these elements is a critical step, it is imperative that a plan(s) for subsequent action is/are generated and that accountability to carry through with agreed upon commitments is inherent. Without the elements of action and accountability, the conference runs the risk of becoming a discussion only. To be most effective, enthusiasm and momentum must be capitalized upon and translated into action and follow-through. To this end, a defined objective of the process is to share conference findings and outcomes of action plans at a future conference and through publication in psycho-oncology journals.

It is recognized that the stakeholder groups are constrained by financial, human, and/or time resources. Sustainability is a necessary consideration for all solutions and future action. The process calls for the development of sustainable action plans, the generation of a list of resources to support the implementation of plans, and includes as a separate step, the appropriate transfer of responsibility to parties who will ensure ongoing sustainability.

The underlying premise of this proposal is that building a community of knowledge exchange and capacity building will represent a positive event in the delivery of psychosocial cancer care for patients and their families. Discussion has occurred with regard to indicators that could be used to define, measure, and demonstrate success.

Plans have been made to extend conference invitations to representatives from other groups, (e.g., mental health), due either to the relevance of their field to that of psychosocial cancer care and/or their group's experience in addressing some of the issues related to developing a community of knowledge exchange, (e.g., developing knowledge translation tools). Inclusion of representatives from other groups has the potential to enrich the solutions and plans that are generated at the conference. Inclusion of representatives from other groups, as well as the publication of conference and action plan results, has the potential to inform other groups about the work occurring within psychosocial cancer care so that its applicability in their respective fields can be considered.

Next Steps

Whether a community for knowledge exchange and capacity building is developed, and what form it takes, are matters to be decided by those attending the proposed conference and their respective groups. Some initial information is available from the results of the previously noted meeting between CAPO Board members and representatives from eleven NGOs. Many questions remain including the kinds of information resources other stakeholders require to contribute to the psychosocial care of patients and families, the kinds of information resources they have to share, and the preferred mechanism for this sharing. However, the findings to date suggest that there may be a role for technology. There are models currently in use by other organizations that can serve as a platform for discussion.

One option is to develop a clearinghouse to serve as a warehouse or repository for evidence-based information and resources that individuals can access as required. A quick scan of the Internet reveals that there are several health-related clearinghouses currently in existence. Many simply function as repositories for information. An alternate model of clearinghouse is that of the Health Promotion Clearinghouse (http://www.hpclearinghouse.ca/). This Nova Scotia based clearinghouse is a partnership venture of government, NGOs, and other community based organizations. It arose from a recognized need for a knowledge and skills information exchange system amongst those working in health promotion. The Clearinghouse enables access to resources including documents, databases, resource lists, and organizations and maintains information on upcoming events, learning, job, volunteer, and funding opportunities, as well as key Nova Scotia health promotion initiatives. The Clearinghouse also maintains list of human resources willing to serve as mentors, speakers, and consultants. The Clearinghouse is staffed with a Coordinator to assist users in accessing the desired resources.

The Canadian Virtual Hospice (http://www.virtualhospice.ca/), components of which are still under construction, provides another model. Akin to an on-line community, this site is designed and tailored for different types of users: clinicians, patients, supporters, and volunteers. Professionals have access to information on supporting patients as well as Canadian palliative care research, researchers, and funding opportunities; answers to frequently asked questions [FAQs]; expert advice; and avenues for dialogue with other professionals via on-line chat and bulletin board options. Patients, supporters, and volunteers are offered similar services tailored for their information needs in addition to an on-line journaling option.

These models differ in terms of intended audience, the resource requirements required to create and maintain them, and the degree of user interaction that is afforded with both the system and with others using the system. The more sophisticated a system becomes in terms of its offerings and staff requirements, the more difficult it may be to sustain. However, a sophisticated system may be of most use to its users.

Conclusions

The existence and format of a community for knowledge exchange and capacity building in psychosocial cancer care is a matter to be decided by those attending the proposed conference and their respective groups. While initial information gathering suggests that that there may be a role for technology, more information is required before any solutions and plans can be developed. There are several clearinghouses and on-line communities being utilized for health-related issues that can serve as potential models for consideration. As with any project, resources and sustainability are important issues for consideration.

Recommendations

Without the necessary information from all stakeholders it would be premature and futile to make recommendations regarding a specific technological solution for the proposed community of knowledge exchange and capacity building. There are a few general recommendations that can be offered, however.

- Ensure that any solutions, particularly those involving technology, maintain a user-centered focus. Use technology to meet the expressed needs of users in a capacity that does not exceed users needs and abilities.

- Avoid re-inventing the wheel. Study existing models already in use for health-related information and resources to assist in choosing the optimal technological solution(s). Explore the possible expansion of sites already developed or in use by partners.

- Establish a plan that addresses key issues including range of services to be offered, staffing requirements if any, membership, ownership, resources, and sustainability.

Relevance to Health Informatics

In assessing the relevance of this internship's work to Health Informatics, it is necessary to put forth a definition upon which an assessment can be based. For this purpose, the definition contained on the website for the Health Informatics program will be utilized.

Prior to the assessment, however, the author wishes to propose some amendments to the existing definition. Health Informatics is defined as a field that “deals with understanding the meaning and use of health information to support clinical care, health services administration, research and teaching” [7]. This definition for the use of health information appears to encompass only those activities occurring within institutions, (e.g., hospitals and universities), and refers primarily to treatment—the support of treatment, distribution/allocation of resources for treatment services, and the generation and dissemination of information and knowledge related to treatment. It is respectfully suggested that the definition be expanded to include the term “health promotion” given the importance of health information in the prevention and reduction of illness and promotion of health. Inclusion of this term would also serve to acknowledge illness prevention and health promotion as integral components of the health**care** system. Further, it would allow for acknowledgement of community-based organizations such as not-for-profits and NGOs that utilize health information in their work.

The website further notes that the Health Informatics program “deals with the management and use of health information” [7] and that “[p]ertinent information is necessary for informed decisions by patients, clinicians and health policy makers” [7]. While the importance of pertinent information for the identified groups cannot be disputed, it is asserted that pertinent information is invaluable for all “health consumers” in their personal quest for optimal health, regardless of whether they are patients or not.

The work of the internship, the details of which have been delineated in an earlier part of this report, included several health informatics related projects and tasks.

- Literature searches for randomized trials were conducted to support the education of patients, researchers, and other clinicians. An understanding of research methods, and the ability to critically assess research methodologies, were required to select higher quality studies from those with less rigorous methodologies. With a wealth of health information available, it is of paramount importance to separate better quality information from poorer quality information for any use whether it is health promotion, patient education, resource allocation, research, etc.

- The Consumer Health Project aimed to educate and teach specific skills to cancer patients and their caregivers via a technology-based medium, (e.g., Web or DVD). The content that was to be imparted had been developed and refined through regular public lectures. Here, evidence-based, pertinent, health information was to be utilized to educate and support clinical care through enhancing understanding of cancer and its treatment, to enable patients and their caregivers to make informed decisions, to teach skills, and to promote health.

  Location of evidence-based information regarding the appropriate use of technology was required to ensure that users would benefit from the same information delivered via a technology-based medium. A plan for the development, prototyping, and evaluation of a “product” was produced. Again, the ability to critically assess research literature was required, as was an understanding of systems design and the principles and practices of user-centered design and evaluation. IT project management principles were key in the development of a plan for development and evaluation.

  The delivery of health information via the use of technologies such as web-based programming or DVD gives rise to a unique set of considerations. Questions arise around how to effectively deliver information that has been traditionally shared in a face-to-face and more interpersonal manner. This is a quintessential health informatics issue as technology becomes an enabler in supporting the dissemination of health information.

- While not directly involved in the development or delivery of the Skills for Healing retreats, exposure to the development of a research strategy to collect and analyze information on the long-term effects of retreat participation was provided. The results of this research may impact the delivery of the retreats, but will also contribute to the literature on the effectiveness of psychosocial interventions. Once in the published literature, these results will serve as a resource to others involved in research, patient care, health services administration, and policy making.

- The proposal, “Creating a Community for Knowledge Exchange and Capacity Building in Psychosocial Cancer Care: Facilitating Collaboration Between NGOs, Professionals, and Researchers”, aims to enhance psychosocial care for cancer patients and their families by enabling seamless psychosocial care, information and support across the cancer journey. At its core, this initiative is intended to enhance clinical care by ensuring that the full complement of patients’ and families’ needs are met and that information required for decision-making is available. The facilitation of collaboration between NGOs, professionals, and researchers aims to improve access to and use of health information.

  As with the other projects, this project required an ability to locate and analyze information. Information on the design of knowledge management solutions presented in HINF 6230: Knowledge Management for Health Informatics [6] was utilized to draft initial plans.

  The proposal details a prime example of a knowledge management issue. As noted, the stakeholder groups are tending to work in silos as opposed to parts of an integrated system. As a result, both services and knowledge are fragmented. Integrating the stakeholders; facilitating the generation and dissemination of information and knowledge; and creating a mechanism to harness and manage that information and knowledge exemplify a knowledge management strategy for ensuring information and knowledge are available to, and usable by, stakeholders. In doing so, a form of Community of Practice may result.

This internship provided the opportunity to apply information and skills learned throughout the Health Informatics program. Course content from Research Methods, Project Management, Knowledge Management, Systems and Issues, and Human-Computer Interaction were most beneficial in completing the tasks associated with the assigned projects. Health informatics principles, concepts, and values were integral to all aspects of the work of the internship as evidenced by tasks such as the dissemination of quality health information for use by patients, clinicians, and researchers; collection of data on health-related interventions for analysis and subsequent publication in the academic literature; exploring the use of technology as an enabler for patient and public education; and addressing gaps in the sharing and dissemination of health information and resources.

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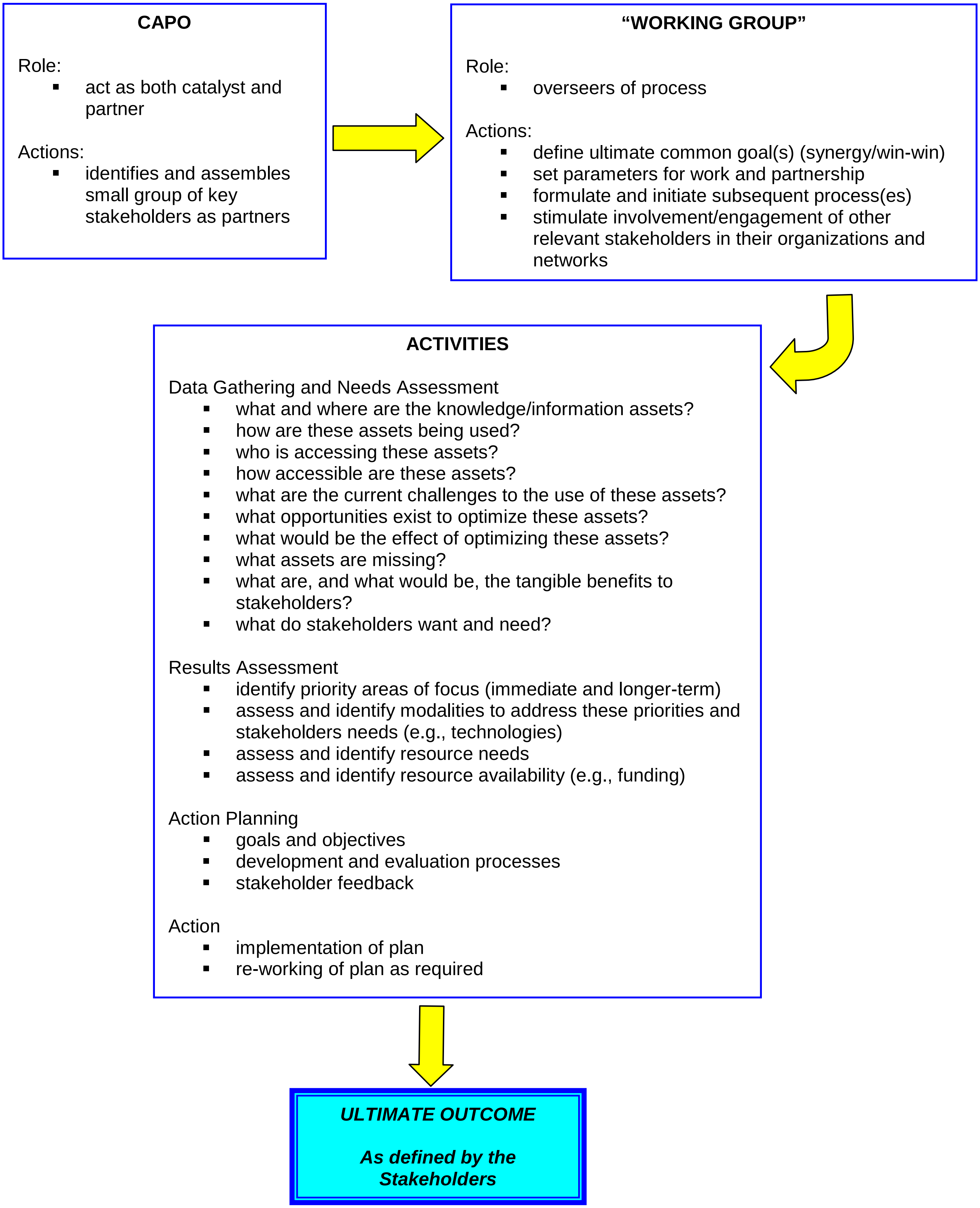
Appendix A



CAPO

Role:
- act as both catalyst and partner

Actions:
- identifies and assembles small group of key stakeholders as partners

"WORKING GROUP"

Role:
- overseers of process

Actions:
- define ultimate common goal(s) (synergy/win-win)
- set parameters for work and partnership
- formulate and initiate subsequent process(es)
- stimulate involvement/engagement of other relevant stakeholders in their organizations and networks

ACTIVITIES

Data Gathering and Needs Assessment
- what and where are the knowledge/information assets?
- how are these assets being used?
- who is accessing these assets?
- how accessible are these assets?
- what are the current challenges to the use of these assets?
- what opportunities exist to optimize these assets?
- what would be the effect of optimizing these assets?
- what assets are missing?
- what are, and what would be, the tangible benefits to stakeholders?
- what do stakeholders want and need?

Results Assessment
- identify priority areas of focus (immediate and longer-term)
- assess and identify modalities to address these priorities and stakeholders needs (e.g., technologies)
- assess and identify resource needs
- assess and identify resource availability (e.g., funding)

Action Planning
- goals and objectives
- development and evaluation processes
- stakeholder feedback

Action
- implementation of plan
- re-working of plan as required

ULTIMATE OUTCOME

As defined by the Stakeholders

Appendix B

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For more information, please contact:

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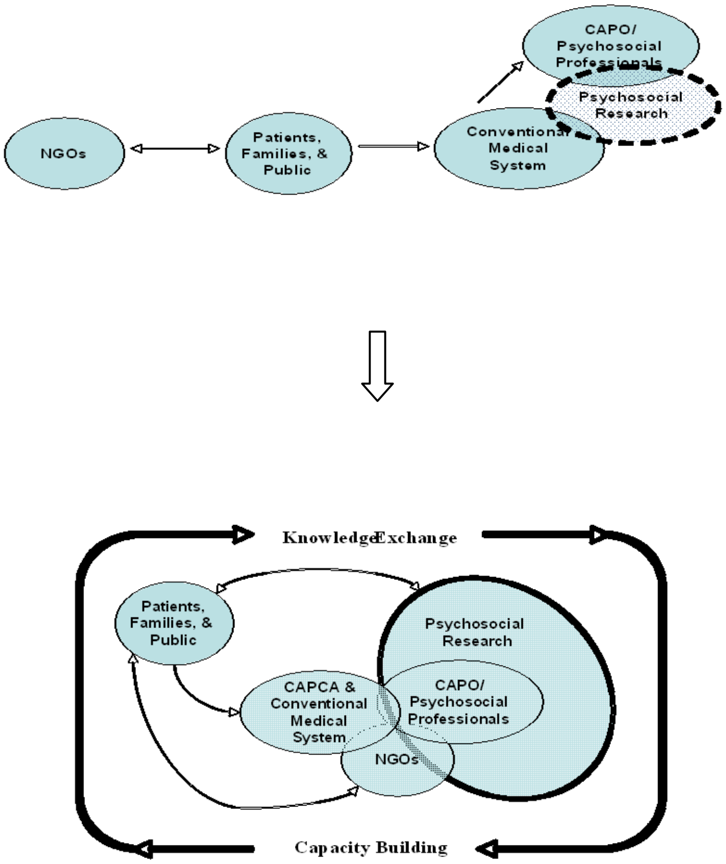
Creating a Community for Knowledge Exchange and Capacity Building in Psychosocial Cancer Care: Facilitating Collaboration Between NGOs, Professionals, and Researchers



Appendix B

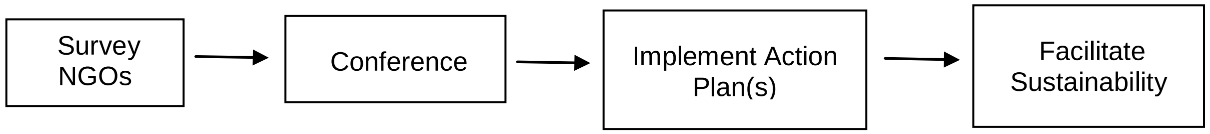
Project Rationale

To ensure seamless high quality psychosocial care and services for patients and families across the cancer journey through collaboration of NGOs, the medical system, and researchers.

Proposal

Steps:

5. **survey** NGOs practices and needs
6. organize and conduct a **conference** for stakeholders in psychosocial cancer care
7. implement **action plan(s)** developed at the conference
8. devolve responsibility for **sustainability**



1. Survey NGOs

Purpose: to collect data from NGOs on their needs and current practices as well as how they evaluate their programs, implement research, and share information

2. Conference

Purpose: to create the foundation for a community of knowledge exchange and capacity building in psychosocial oncology

Objectives:

6. to bring together key stakeholder groups in psychosocial cancer care to develop the vision of seamless integrated care and to foster ongoing working relationships
7. to share NGO survey results and generate an overview of current practices as well as barriers and enablers in knowledge exchange and research between NGOs, psychosocial and medical professionals, and psychosocial researchers
8. to develop (a) sustainable action plan(s) for creating a community for knowledge exchange and capacity building in psychosocial cancer care
9. to generate a set of resources for participants, including funding, to support them in implementing the sustainable action plan(s)

10. to share findings from this conference and outcomes from the action plan(s) at the next annual CAPO conference and through publication

3. Implement Action Plan(s)

Purpose: to further the vision of seamless integrated care developed at the conference by taking active steps to create the community of knowledge exchange and capacity building as developed by conference members

Further detail cannot be provided here as these will be developed at the conference.

4. Facilitate Sustainability

Purpose: to ensure lessons learned and ideas generated at the conference become part of the normal practices of the stakeholders

Conference organizers will be responsible for facilitating the transfer of responsibility to partners who will ensure sustainability.

Why This Initiative is Needed Now

Meeting the medical needs of cancer patients is essential. However, the psychosocial needs of both patients and their supporters are increasingly recognized and frequently met by NGOs. There is little published information on how psychosocial needs are being met and no mechanism to share information among the “pillars” of psychosocial care: CAPO/psychosocial health professionals, NGOs, researchers, and the conventional medical system. We propose the creation of a knowledge exchange community to facilitate information sharing, knowledge translation, collaboration, and capacity building among stakeholders. Ultimately, patients and their families will benefit from a more integrated and collaborative system of psychosocial cancer care.

The Canadian Association of Psychosocial Oncology [CAPO], which brings together health professionals, clinicians, researchers, educators, and others [1], is strategically placed to advance this initiative.

NGOs play a key role offering: advocacy (government, health care professionals and academics), research, fundraising, education (patients, health professionals), patient support and information, prevention, and communication via websites and newsletters. They facilitate peer support through groups, discussion boards, retreats, and mentoring programs, promote wellness and enhance coping skills through yoga, meditation, and visualization, foster emotional expression through creative outlets such as art, music, and journaling, and offer skills training that can be used to assist others (such as training volunteers in mentoring programs).

Research is essential in order to demonstrate the importance of psychosocial resources and to determine needs and the most effective practices, as well as to answer other questions. Yet researchers rarely network with NGOs or patients, resulting in a lack of information about the research needs of NGOS, a lack of access to research participants, and difficulties in competing for limited funding for psychosocial research.

Physicians play a central role in treating cancer but do not have the time to deal with all of their patients' psychosocial needs, nor to keep up with the rapidly growing field of psychosocial research and practice.

The Current Reality: Fragmented Psychosocial Care

There is little collaboration or communication between these critical pillars of psychosocial cancer care and no framework to facilitate interconnections. The result is a fragmented system in which each component is functioning in relative independence from the others and requiring patients and their supporters to go through multiple channels to access the needed psychosocial support.

Results of a recent patient survey [2] reveal that patients' emotional support needs are not well addressed in Canada. Patients reported that they had not received enough information about emotional and relationship changes nor had they been linked with an oncology professional to help with their fears. At the same time, Canadians are turning to the Internet for health information in increasing numbers [3,4] often to NGO sites. An additional problem is the unequal access created by variations across the country in staffing levels, access to relevant disciplines, and programs, for both professional and volunteer-based services, whether they are offered within or outside cancer centres [5].

Patients and their supporters interact primarily with the NGOs (to meet their psychosocial needs) and the conventional medical system (to meet their physical needs). The relationships between the pillars of care are linear and sequential, with each working in relative isolation. Despite the impetus in Canada for a more integrated approach to research, (reflected in funding decisions), researchers are often on their own in developing their research, with no structure that would help to connect them to groups that have vital research questions and would help to convey research findings back to the group.

The Vision

We suggest the need to create a community with consistent processes for knowledge exchange in which each pillar becomes a partner, aware of the other partners and their contributions, working as part of an integrated and collaborative system in which knowledge is shared and inherent expertise recognized and utilized. This knowledge community will together create **seamless psychosocial care, information and support across the cancer journey for patients and families**.

The Solution: Creating a Community for Knowledge Exchange and Capacity Building

Our action plan, outlined above, is intended to transform psychosocial cancer care from a fragmented knowledge system to a connected network which will increase opportunities for sharing knowledge and supportive collaboration. As partners learn from the perspectives and expertise that each brings to the community, the capacity to create higher quality programs and services in psychosocial cancer care, reducing gaps, will ultimately benefit patients and their supporters.

Appendix B

Progress to Date

The first step in the development of this community has been taken. Following the 2006 CAPO Conference, representatives from 11 partner organizations met with CAPO to discuss what it could do to support them. These founding organizations were: Canadian Breast Cancer Network, Canadian Cancer Society, Colorectal Cancer Association of Canada, Lung Cancer Canada, The Leukemia and Lymphoma Society of Canada, National Ovarian Cancer Association, Ovarian Cancer Canada, Wellspring, RealTime Cancer, Willow Breast Cancer Support Canada, and Hope and Cope. All parties agreed on the need to develop 1) mechanisms to share information, (e.g., electronic resources, workshops, and training sessions); 2) consistent standards, (e.g., reviewing and approving educational materials, developing a standardized curriculum for volunteers); and 3) processes for research collaboration and knowledge translation, (e.g., implementing research findings on a practical level). The parties agreed to hold a partnership conference at CAPO 2007.

This working document is a vital second step, describing an opportunity to enhance psychosocial cancer care for patients and their supporters. Your involvement is important for taking the next steps toward making the community for knowledge exchange and capacity building a reality.

References

[1] Canadian Association of Psychosocial Oncology. Welcome. Retrieved June 22, 2006 from http://www.capo.ca/eng/about_capo.asp

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