Supportive Cancer Care Programs: Further application of the Knowledge Exchange Decision Support (KE-DS) Toolkit Final Report, 2009

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Executive Summary

The Canadian Strategy for Cancer Control (CSCC) was established in 1998 to make recommendations for needed improvements in the cancer control system in Canada. The Canadian Partnership Against Cancer (CPAC) has a mandate to implement the Canadian Strategy for Cancer Control goals to create change in the cancer care system in Canada. The Cancer Journey Action Group\(^1\) (CJAG) focuses exclusively on supportive care for cancer patients who are increasingly surviving their disease. The KE-DS Toolkit is one of a number of toolkits commissioned by CJAG.

An environmental scan of cancer survivorship in Canada prepared for CJAG documents that accessing cancer care is a complex and, at times, confusing and disjointed experience for patients and their families (Ristovski-Slijepcevic, April 2008). In light of increased demand for services for survivors and their families and support providers, cancer care providers both internationally and nationally are shifting to a chronic disease management strategy – in essence a long-term care strategy. The challenge facing providers is how to best approach this problem.

The KE-DS Model and Toolkit elaborate how alternative choices may have diverse consequences that often stretch far beyond immediate patient outcomes. The model provides a synthesis of the socio-medical dynamics in policy and practice; it adopts a critical perspective which delineates issues of power and dominance, as well as describing the impact of the intervention (i.e. supportive cancer care). Best practice decisions occur in a series of fairly well-defined stages (that one could also repeat and backtrack): 1) recognition of problem, 2) formulation of possible intervention, 3) generation of alternatives, 4) information search, 5) judgment or choice, 6) action, 7) feedback. This broad “problem solving” approach is the one adopted for the Model to ensure a comprehensive understanding of the specific problem/deficit as well as a thorough examination of the consequences of alternative courses of action.

The proposed model is comprised of several component dimensions/contexts, and provides a comprehensive, transparent approach to best practices. However, it is designed with ease of application in mind and should not be too onerous to use. The model for decisions in health care was developed incorporating four key dimensions:

1) Population and health services context
2) Economic context
3) Broad social context (including ethical, legal, and political concerns)
4) Quality of scientific knowledge about the health issue and/or its intervention

The Model process assumes the inclusion of all stakeholders and it provides the opportunity to align local (or sub-population, or stakeholders) “wants” with population health needs, provides

\(^1\) One of eight action groups comprised of collaborative networks of experts created to address CPAC priority areas.
guidelines within which the appropriate information is sought and examined, and draws on a number of disciplinary perspectives, incorporating theories of epidemiology, sociology, economics and systems science. It is a means of applying critical theory to health care evaluation.

The purpose of this report is to describe and discuss two supportive care programs through the lens of the Knowledge Exchange Decision Support (KE-DS) Toolkit:\(^2\):

1) The Cancer Transitions program developed by The Wellness Community and the Lance Armstrong Foundation is one approach to meeting the needs of cancer survivors and their families. Funded by CPAC and piloted in four communities across Canada, Cancer Transitions aims to assist survivors in making the transition from active treatment to post-treatment care by focusing on emotional well-being, exercise, nutrition, medical management, and survivorship care planning (Ward 2009),

2) The Breast Cancer Recovery Course program specific to breast cancer survivors implemented by the Breast Cancer Supportive Care Foundation (BCSSF) in Calgary. This innovative, professionally facilitated change management course explores physical, emotional, mental, social and spiritual wellness and empowers participants to incorporate self care, nutrition, physical activity and stress management techniques into a personalized healing plan designed to transition patients from illness to health and wellbeing.

Utilizing the ethnographic approach of ‘thick description’, each project team (3 CT programs and BCSSF) participated in a retrospective exercise where they considered the application of the KE-DS Toolkit to the development and implementation of their respective programs. The report documents the implementation of the Knowledge Exchange Decision Support Toolkit at these sites as part of the first phase of CIHR funded activities in knowledge exchange and transfer.

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\(^2\) Knowledge exchange (KE) as used in this context derives directly from the current CIHR definition (CIHR, 2008). The Knowledge Exchange Model for Supportive Care (2009) is designed to show the complex set of interactions between creation, synthesis, assessment and evaluation of relevant information, strategies for dissemination and translation for a range of stakeholders, and the collection, storage and facilitation of access for all users.
Introduction

The Larger Context: Commitment to Supportive Cancer Care

Addressing the needs of cancer survivors has become a major priority for a number of cancer programs both internationally and in Canada. Cancer patients are increasingly surviving their disease\(^3\), requiring that cancer care providers switch to a chronic disease management strategy – in essence a long-term care strategy. In the context of post-treatment, it has been recognized that the formal cancer system is “front end loaded” with limited program development or resources invested in survivorship programs. There is an increased demand for services for survivors and their families and support providers. The challenge facing providers is how to best approach this problem.

The Canadian Strategy for Cancer Control (CSCC) was established in 1998 to make recommendations for needed improvements in the cancer control system in Canada. The Canadian Partnership Against Cancer (CPAC) funded by the Federal government in November 2006 is an independent corporation charged with accelerating action on cancer control across Canada. CPAC has a mandate to implement the Canadian Strategy for Cancer Control goals to create change in the cancer care system in Canada. In order to draw on cancer control knowledge and expertise widely dispersed throughout Canada’s health care system and make it readily accessible to all stakeholders, collaborative networks of experts were established for each of the priority areas determined by the Canadian Strategy for Cancer Control. Of the eight Action Groups created to implement the recommendations, the Cancer Journey Action Group (CJAG) led by Dr. Margaret Fitch focuses exclusively on psychosocial and supportive care.

The focus of the Cancer Journey Action Group (formerly Rebalance Focus) is to ensure improvements in quality of life through psychosocial and supportive care interventions, and to help shift the emphasis in cancer care from a medical approach to a more patient/family/supporters centred approach. The Cancer Journey Action Group established evidence-based practice that draws on knowledge; its generation, creation, evaluation and exchange, and was of primary importance to this shift in emphasis. A multidisciplinary team of academics and researchers collaborated with this Action Group and were successful in obtaining CIHR funding for a program of research entitled: Promoting Equity in Access to Cancer Supportive Care (Ref. Grant #AQC-83559). In this research program the aim is to delineate the concept of access and stimulate policy efforts to improve access to supportive care. The definition of access, adapted from the literature, encompasses four dimensions: availability, utilization, effectiveness and equity. The focus of this program of research is on supportive care at specific transitions in the cancer care continuum. The two most important are the transitions at the point of diagnosis and at the point of completion of primary treatment when the patient moves from the acute care system to the community care system and home. The second transition also corresponds to the period now called ‘survivorship’. An environmental scan of cancer survivorship in Canada prepared for CJAG illustrates that accessing cancer care is a complex and, at times, confusing and disjointed experience for patients and their families (Ristovski-Slijepcevic, April 2008).

Due to increased rates of cancer survivorship, CJAG has identified the development of improved approaches to cancer survivorship care planning as a major priority. At the present time, there are no evidence-based psycho-social emotional services available for survivors in Canada. As research illustrates that “one in three survivors will have suffered clinical depression or debilitating anxiety at some point along the cancer trajectory

\(^3\) Cancer survivors represent 2.5% of the Canadian population, which translates to approximately 825 000 cancer survivors living in Canada today (Ward 2009:6).
and required referral to a trained professional”, the need for programming that is professionally led and with a psycho-educational focus is urgent (Ward 2009:6). In an effort to meet this need, the BC Cancer Agency (BCCA) created the Canadian Survivorship-Cancer Transitions Action Group (CS-STAG) to address program planning, development and evaluation of survivorship initiatives. Two initiatives were considered/assessed during their pilot process.

1) Cancer Transitions, a program developed by the Wellness Community and the Lance Armstrong Foundation that aims to help survivors make the transition from active treatment to post-treatment care[^4], is the first of these initiatives. The Canadian piloting of this program occurred in four communities across the country.

2) The Breast Cancer Recovery Course, designed by the Breast Cancer Supportive Care Foundation (BCSCF), a community based medical initiative, is in the final stages of curriculum development and piloting in Calgary.

This report considers the planning and implementation processes experienced by three of the four CT project teams (the fourth team, Wellspring in Toronto, decided not to participate in the KE portion of the project), as well as the Breast Cancer Supportive Care Foundation (BCSSF) initiative in Calgary. Each site reflection is unique to the experiences of the facilitators and project team at that site. They are offered here not to directly compare their experiences, but to gain an appreciation of the manner in which the geographical and social environment affect the planning and implementation of psycho-social supportive cancer care programs. A better understanding of the efficacy, feasibility and impact of survivorship programs on patients and their families will lead to improved understanding of the potential benefits of psycho-educational programming in relation to supportive cancer care.

In order to facilitate this understanding, a key building block in the CIHR funded research program is the creation, application and evaluation of a Knowledge Exchange Model for Supportive Cancer Care. This Model fosters evidence-based clinical practice, system management, and health policy development in cancer prevention and control in general, and with a focus on patients’ (and their families’) needs in particular. The implementation of the Knowledge Exchange-Decision Support Toolkit (KE-DS Toolkit) recently developed for CJAG (Kazanjian, Howett & Chan 2009) is part of the first phase of CJAG/CIHR funded activities in Knowledge Exchange and Transfer (Kazanjian and Howett 2008). As part of this 2009 series of reports, this report describes and discusses the Cancer Transitions and BCSCF program that were funded by CJAG through the lens of the KE-DS Toolkit.

Knowledge Exchange, the KE Model for Supportive Cancer Care

CJAG’s focus on the generation, creation, evaluation and exchange of knowledge is central to their mandate to shift the emphasis of cancer care from a tumour-centred approach to a person-centred one that provides supportive care, as appropriate.

Knowledge Exchange

Knowledge Translation (KT) and Knowledge Exchange (KE) are relatively new concepts being used in health services and policy research. The term KE is based on the premise that a gap exists between the production of research knowledge and its implementation as evidence-based practice, planning and decision making. The process of bringing research evidence to practice has yielded various frameworks, models and toolkits for KE in many disciplines. All delineate, in various ways, a complex set of interactions between the creation of new information, synthesis, assessment and evaluation of that information, strategies for dissemination and translation for a broad range of stakeholders, as well as the collection, storage and facilitation of access for all users.

Knowledge exchange (KE) as used in this context derives directly from the current CIHR definition (CIHR, 2008). The Knowledge Exchange Model for Supportive Care is designed to show the complex set of interactions between creation, synthesis, assessment and evaluation of relevant information, strategies for dissemination and translation for a range of stakeholders, and the collection, storage and facilitation of access for all users (Kazanjian and Howett:2008).

Traditionally, within evaluation research, a full-scale needs assessment would provide the required evidence on questions of health service need. For the purposes of moving to the next stage of our systematic process, seeking at least a few answers to what supportive cancer care needs are is appropriate. A need exists when the practitioner or policy maker has evidence that there is a discrepancy between an acceptable situation and the existing situation. Is there such a discrepancy? Is there any public expression of such a need and/or public support for filling the gap?

Need identification is the process of describing the health care requirements of a target population and the solution to a current problem. Evaluation of need pertains to assessment of the importance and relevance of the problem and the solution. Thus, needs analysis includes problem identification, solution identification, and ultimately, evaluation of problem and solution.

In the broadest context, confronted with a choice of interventions or programs, practitioners and policy makers may have a number of possible alternatives; selecting the alternative that includes notions of equity and utility and is grounded in principles of social justice is the most appropriate. A decision model that reflects these attributes and rationalizes choices between approaches or strategies in terms of equity and utility is arguably more useful. The rationale for the development of an evidence-informed model is centred on basic principles of justice in health care: equitable access to all effective health care which society can afford.
The Knowledge Exchange – Decision Support (KE-DS) Toolkit: Defining and Refining

The KE-DS Model elaborates how alternative interventions may have diverse consequences that often stretch far beyond immediate patient outcomes. The Model and Toolkit provide a synthesis of the socio-medical dynamics in policy and practice; it adopts a critical perspective which delineates issues of power and dominance, as well as describing the impact of the intervention (i.e. supportive cancer care). It is a decision support tool with a series of fairly well-defined stages (that one could also repeat and backtrack): 1) recognition of problem, 2) formulation of possible intervention, 3) generation of alternatives, 4) information search, 5) judgment or choice, 6) action, 7) feedback (Kazanjian and Pagliccia, 1998). This broad “problem solving” approach is the one adopted for the proposed Model to ensure a comprehensive understanding of the specific problem/deficit as well as a thorough examination of the consequences of alternative courses of action.

The proposed Model is framed to be a deliberation process with consistent dimensions, with defined yet modifiable indices of each dimension and an accompanying evaluation/measurement component. The four dimensions are:

1. Population and health services context
2. Economic context
3. Broad social context (including ethical, legal, and political concerns)
4. Quality of scientific knowledge about the health issue and/or its intervention.

Depending on the subjective importance of the dimension, different weights can be assigned to the dimensions by the decision-maker.

The KE-DS Model (Figure 1) has prominent features that exist in other knowledge translation models (Tetroe & Graham et al. 2008; Logan & Graham 1998); furthermore it offers a more functional view of knowledge exchange. Firstly, by virtue of its comprehensive nature with the coverage of all dimensions of concern, the Model process assumes the inclusion of all stakeholders and it provides the opportunity to align local (sub-population or stakeholders) “wants” with population health needs. Secondly, it provides guidelines within which the appropriate information is sought and examined. Different forms of information and knowledge are acknowledged, and there is an attempt to integrate and synthesize them (the dotted line around the evidences used for each context signifies this integration, Figure 1). Thirdly, the Model draws on a number of disciplinary perspectives, incorporating theories of epidemiology, sociology, economics and systems science; and applies critical theory to health care evaluation.
Figure 1: Knowledge Exchange for Supportive Cancer Care Model & Toolkit Overview

KE Model for Supportive Cancer Care
Model & Toolkit Overview

Assign relative weight of importance:

- Population Context
  - Population at risk
  - Population impact
  - Health concerns using indicators

- Economic Context
  - Economic concerns
  - Economic variables

- Social Context
  - Social scope/compass
  - Legal Impact
  - Political Impact
  - Ethical impact
  - Equity Impact

- Evidence on SCC & its quality
  - Areas of application of scientific evidence
  - Scientific value of evidence/technology
  - Summarise scientific merit of evidence or technology

Define/Identify:

Quantify:

Evaluate:

- Implement new policy or practice

- Is the balance of costs & benefits within acceptable range?
  - Yes
  - Postpone adoption of policy or action
  - No
Methodology
As the aim of this project is to gain an understanding of the use of the KE-DS Toolkit in the implementation phases of different cancer survivorship groups, the research team utilized a method of analysis grounded in cultural anthropology, where investigating people’s experiences is the primary focus of the discipline. Established by Clifford Geertz in the 1970s, “thick description” is an ethnographic approach to elucidating an understanding of a specific event or behavior within the social context that it occurs. The use of thick description is not meant to expound an explanation for why people do the things they do, but rather to gain an understanding of the social context in which it occurs and the meanings that people ascribe to their actions, beliefs and symbols (Geertz 1973). Following this approach, it is impossible to understand an event, institution or behavior without also gaining an understanding of the context, or “web” of meanings, in which the event, institution or behavior occurs. Thus, a description rich in detail is necessary in order to grasp the nuance and subtleties of the situation. States Geertz: “Culture is not a power, something to which social events, behaviors, institutions or processes can be causally attributed; it is a context, something within which they can be intelligibly –that is thickly – described” (1973:14).

Following Geertz’s assertion that the context is equally as important as the behavior itself, the following sections of this report aim to illustrate the use of the KE-DS Toolkit within the social environment that each of the project teams operated within. A detailed retrospective account of their experiences allows for an understanding of the subtleties of the process of planning and implementing an initiative in a health care setting. Their experiences, therefore, are unique to the context in which they occurred and cannot be directly compared. Their reflections on the use of the KE-DS Toolkit will lead to a better understanding of the strengths and weaknesses of the model in terms of both applicability and ease of use. The reflections from the project teams were collected through interviews, informal discussions and correspondence with project team staff and management, and a review of project documents.
Commitment to Supportive Cancer Care: Cancer Transitions

Cancer Transitions is a trained-facilitator led program that provides tools to address the physical, psychosocial and practical needs of cancer patients post-treatment. Cancer Transitions is based on the Patient Active Concept™ that states that “people with cancer who participate in their fight for recovery from cancer will improve the quality of their life and may enhance the possibility of their recovery”\(^5\). The program has been piloted at fifteen locations in the United States, and this is the first time it is being piloted in Canada. The Canadian sites include: Northern Health Authority – Prince George, Hope and Cope - Montreal, Wellspring – Toronto, and BC Cancer Agency - Vancouver Island.

The program consists of six 2 ½ hour sessions, offered once per week for six consecutive weeks. There is also a follow-up “Booster” session held four weeks after the core program ends. All sessions allow time for discussion and participants receive a set of published materials to assist them with their goals during and after the program.

The Cancer Transitions program requirements are:
1. A trained facilitator
2. Experts to speak about specific topics in the program (e.g. nutrition, medical management) or lead specific activities (e.g. exercise specialist).
3. Dedicated space for sessions
4. A site budget and plan for marketing and recruitment
5. A Research/Contact person (to take ownership of evaluation documents and to evaluate program implementation). In November 2008, this component was revised and a BCCA staff member collected and stored the completed evaluation documents.

The goal of the Cancer Transitions program is to present participants with a ‘survivorship skill set’ (information, skills, and resources designed to place the focus on patient health). The desired outcome is that the participants ‘will feel a renewed sense of energy and ability to cope with life after treatment’. The sessions focus on six core elements: exercise, nutrition, emotional and social issues, medical management and moving forward.

**Session 1:** Get Back to Wellness: Take Control of Your Survivorship  
**Session 2:** Exercise for Wellness: Customized Exercise  
**Session 3:** Emotional Health and Well-Being: From Patient to Survivor  
**Session 4:** Nutrition Beyond Cancer  
**Session 5:** Medical Management Beyond Cancer: What You Need to Know  
**Session 6:** Life Beyond Cancer: Next Steps Towards Survivorship

In order to test the feasibility and effectiveness of the Cancer Transitions program, “participants completed validated self-reported questionnaires about the program content and their physical and psychosocial well-being at the first and last session of the program. Program feasibility was also assessed by participant recruitment and attendance” (Ward 2009:19). Each Cancer Transitions project team was responsible for administering these measures. Completed questionnaires were mailed to the BC Cancer Research Team where analysis is ongoing. The following indicators were utilized to assess the impact of the program:

\(^5\) [http://www.thewellnesscommunity.org/fm/About/Founding-Principles_1.aspx](http://www.thewellnesscommunity.org/fm/About/Founding-Principles_1.aspx)
• Program attendance and completion
• Change in patient health status questionnaire
• Quality of life measures
• Patient satisfaction through anecdotes and narratives
• Documented change in patient ability to exercise
• Documented change in ‘quality of life’ – patients expressed change in point of view
• Dissemination of medical information to patients and supports
• Nutritional strategy uptake

As mentioned, the piloting of the Cancer Transitions program was funded by CPAC. A breakdown of the operational costs is as follows (Ward 2009:46):

**Human Resources approx: $2500**
- Facilitator/Leader: $200 per session x 6 = $1,200
- Exercise Leader: $200 x 1, $75 x 5 = $575
- Nutrition Leader: $200 x 1 = $200
- Medical/Nursing Leader: $200 x 1 = $200
- Administration: $300

**Material Resources approx: $1,500**
TWC direct printing costs (US $):
- Participant Workbooks: $25 each
- Facilitator Guide: $85 each
- Shipping (US to Canada): $100
- Pedometers (optional purchase): $10 each
- Other site resources: $500

Based on the above estimates of site and material costs the program can be offered for a minimum of $4,000.

**Sustainability Costs/year:**
- Facilitator Training/Orientation (ideally 2 trained per site):
  - $500, plus $100 x 6 to observe sessions = $2,200
- Promotional Material: $1,000
- Total estimate of sustainability costs on a yearly basis is $3,200
Northern Health Authority, Prince George

Background
In 2005, BC Cancer Agency (BCCA) and Northern Health (NH) published the final report of a joint initiative designed to address the issue of cancer care in the North of BC. The Northern Cancer Control Strategy\(^6\) was the result of information collected from a series of meetings with stakeholder groups and community-based agencies, community meetings and patient focus groups. Supportive Care and Rehabilitation are primary components of the Regional Cancer Program projected for Northern Health although supportive care and palliative care services tend to be fragmented and differ by community.

The Northern Health Authority currently serves the largest geographical area in British Columbia. The region is primarily rural with patients and their families facing challenges in climate and proximity to cancer services. The health authority has organized cancer services in the major centre, Prince George as well as smaller regional cancer chemotherapy services.

Currently, there are no oncology psycho-social programs anywhere on spectrum at Northern Health. There is some access to social work services at the Prince George Regional hospital for oncology patients, but this is limited. As well, some people may have access to mental health and addiction services through community agencies and some employers may have employee counseling services available through private practitioners. The Canadian Cancer Society offers support services in the North and in Prince George and the area. There are no cancer support groups because they are unsustainable in this community. Prince George Regional Hospital cancer care unit has one oncologist. Northern Health has 9 chemotherapy clinics not including Prince George. There is a program to train family physicians (GPO) in oncology – and there are five trained in Prince George. There is one Regional Cancer Care Social Worker whose mandate includes a component of implementing psychosocial programming throughout NH.

Establishing the Need
The Northern Health rationale for offering this program in Prince George was twofold:

1) Patient-driven requests:
Nursing staff at the PGRH Chemotherapy unit recognized that patients were visiting the unit long after therapy was completed in order to maintain a connection to the staff and access the assistance of the social worker. For example, a few patients who had completed their treatment requested that the VAD\(^7\) not be removed so that they could return to have the line flushed. In July 2008, staff solicited

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\(^6\) Northern Cancer Control Strategy:
A Joint Initiative of the British Columbia Cancer Agency and Northern Health: Final Report March 2005

\(^7\) Vascular Access Catheter
patient feedback and recognized that these issues were the result of transitioning from clinical treatment.

2) Connection to Provincial Strategy/BC Cancer NH Cancer Control Strategy
Adjusting the focus of cancer care to a patient centered focus is the initial step to implementing a holistic patient-centred cancer care as a long-term care perspective. The NH Cancer Control Strategy gives a mandate of program development, to address patient needs before, during and after treatment.

Site Description
The Northern Health Cancer Transitions program ran from January 31, 2009 to March 7, 2009. The Booster session was held on March 28, 2009. The facilitator was a social worker with input from a contract fitness advisor, a doctor (GPO) and a Registered Dietician. The facilitator had the support of the research evaluation coordinator at PGRH who also assisted her with the ethics application and review process.

The program ran at PGRH on Saturday mornings in a dedicated space (the room was changed after the 1st session to accommodate more people). Of the 19 initial sign-ups, they had 17 participants (1 male, 16 female). The schedule of expert speakers was changed at this site to reflect availability of resource people. Recruitment was open to adult cancer patients who had completed surgical, chemotherapy or radiation treatment for cancer who resided in a 100-200 km radius of Prince George. Marketing of the program was through the media: local newspapers in Prince George, Vanderhoof and Quesnesl, and local television and radio stations.

The NH site required a large media presentation which consumed half of the program budget. Media outlets utilized included the Prince George CKPG local television news, both Prince George newspapers as well as municipal newspapers, 2 radio stations in Prince George in addition to radio stations in Vanderhoof and in Quesnel. The thorough promotion strategy was necessary as PGRH sees only patients undergoing chemotherapy – there are therefore cancer patients in the target radius that have completed their cancer treatment elsewhere. There is no potential walk-through contact as these patients often have no connection to the cancer care unit and services. As well, there are nine other chemotherapy sites in the NH region: Vanderhoof, Quesnel, Ft St John, Smithers, Terrace, Prince Rupert, Dawson Creek, Kitimat and Queen Charlotte Islands.

Identifying Stakeholders
Health care practitioners, social workers and patients were all considered stakeholders by the project team.

Population of Interest
The population of interest was any patient who had completed cancer treatment. The demographic of the group included 16 women and 1 man, a mean age of 57 years, 81.3% were married or had a partner, 6.3% had a college degree and 43.8% were not employed or were retired.

The team anticipated that a large number of breast cancer patients would attend as this is generally a group who actively participate in supportive cancer groups. The cancer diagnosis of the group was: 8 breast, 2 colon/rectal, 1 endometrial, 1 lung, 2 non-Hodgkin’s lymphoma, 1 thyroid, 1 Hodgkin’s lymphoma. The mean time since treatment was 8 months, 100% of participants had one or more co-morbid condition, there were no smokers, and 25% had a normal BMI; 31% overweight; 44% obese.
Participants had ideally completed treatment; however, two participants were actively undergoing chemotherapy. This decision to include these patients was made as there was still space available for participants and there were no alternative programs available.

The team hoped to attract participants from all over the surrounding area as services available in these more remote communities are limited or non-existent. A review was conducted to brainstorm strategies for attracting participants from remote areas. One strategy attempted was the use of the NH Cancer Connection bus to facilitate transportation from communities that were relatively close to Prince George (such as Quesnel and Vanderhoof); however it was not successful. As well, the team explored the option of providing the service via Telehealth video conferencing; however, this too was not possible due to the logistics of the technology and not having a trained Telehealth person on site. In the end, participants who did not live in the Prince George or surrounding area were given a $20 stipend per session. In the end, 20% of the participants lived outside of Prince George and traveled from 100km to 200km to attend sessions.

The implementation strategies were tailored to address the needs and social context of the community. Promotion of the program was done through local media (newspaper, radio, TV) as poster campaigns were deemed ineffective based on previous experiences of the facilitator. The facilitator also noted that as Prince George is a “last minute city”, meaning people sign up for programs at the last moment possible, advertisement occurred in the 2 weeks leading up to the start date. 75% of participants signed up the week before the program began.

Population Impact

The focus of the Cancer Transitions program is to facilitate the enhancement of the participant’s quality of life by providing psycho-social services and practical living advice, to decrease the impact of cancer and to improve participant’s nutritional and physical activity level. This initiative is part of an approach to shift health care approach from a short term, clinical focus towards a long-term, chronic disease management strategy.

Participants’ reflection on the program illustrate that their participation resulted in a number of benefits, many of which are difficult to measure. Some patients experienced an improved quality of life as a result of receiving accurate information and an increased understanding of their condition. For example, one participant believed that the swelling she experienced was the result of scar tissue build up. After discussing this with the doctor at a session, she learned that the swelling could likely be from a need to have the lymph nodes drained. After receiving lymphatic drainage, the swelling and discomfort reduced considerably and she reported a higher quality of life as a result. Another participant described herself as being somewhere between the ‘Lost and Found’ section – this was her “new normal”.

Other patients noted a sense of comradeship – one participant attended a session despite having undergone a mastectomy two days earlier. She explained that she felt a strong need to be there, both for herself and for the other group members. The following week another participant explained that despite feeling down and not wanting to go outside in the -30 weather, she made the effort because ‘if a woman with a mastectomy can drum up the energy, so could she’. In fact three participants made every session despite having to drive between 100-200 km through snow storms and -30 weather. Other examples of comradeship include the sharing of resources (such as cookbooks, types of food and walking sticks) that participants had found particularly helpful, as well as sharing experiences such as having difficulty remembering books once read. Participants also exchanged numbers and email addresses.
Some participants experienced a sense of hope. One participant commented that in the past, family and friends often asked her to make plans for the future, something that she did not do. Now, however, her experience in the Transitions program has encouraged her to make summer plans. Participants also expressed a feeling of accomplishment and realization. One woman noted that she never took the time to realize what she had been through, and attending the program allowed her the opportunity to take time for herself and to cry. Another woman noted that she was proud of herself for continuing to attend sessions despite feeling overwhelmed with negativity.

Participants also noted the positive effect of watching others in the group improve their physical fitness – one participant noted that it was inspiring to see a participant who could barely complete 2 squats in week one complete 5 squats in week three. Participants also celebrated when one woman was able to vacuum when the previous week she was not. The fitness expert also noted a change in her own perceptions – she had asked participants to complete 10 squats during the first session when most were not able to complete 2.

The fitness segment is a substantial component of the Cancer Transition program, and in general participants greatly appreciated it. The fitness component was often extended an extra fifteen minutes to a half hour due to participants’ interest. The facilitator believes that there are a few reasons for this interest: 1) there are very few opportunities and resources available for participants to engage in exercise; 2) because of this limited exposure, participants required more time to become familiar with the activities; and 3), participant’s level of fitness varied substantially, thus the fitness expert needed to vary techniques and exercises to meet the needs of all patients. Feedback from patients included a desire for a video of the exercises, as well as exposure to alternative forms of exercise such as NIA (a form of exercise that involves stretching, movement and dance), Yoga and Pilates. The fitness expert noted that fitness bands are a versatile, affordable and easily transported fitness tool that is particularly well suited for those living in areas where access to a gym can be limited.

While the main focus of the Transitions program is the individual, the impact of cancer is also experienced by family and friends. Team members noted anecdotal stories and other types of feedback as a way to consider the effects of the Transitions program on the participant’s family and friends. For example, after the session on Well-Being in which communication with family members was discussed, a patient approached the facilitator to discuss her own mother’s well being. The participant had made the decision not to share her full diagnosis with her mother, nor the complete outcome of her treatment. The facilitator encouraged the participant to discuss this information with her mother. Later the participant reported back that her mother was doing much better after she had discussed with her the details of her cancer experience. Another participant explained how her sharing of information with friends resulted in their commenting that they would also like to attend sessions as the general health information (on nutrition, exercise) was positively impacting their lives.

The Transitions Program seemed to offer participants the opportunity to take time for themselves to consider the supports and resources available. At the conclusion of the program during the “final closing circle”, participants expressed gratitude for having the opportunity to put all of the little bits of information that they had encountered or come across during their experience together.

**Social Context**
Considering the social contexts of Prince George is very important, particularly when promotion strategies are concerned. It was important to establish that the Cancer Transitions program was not simply a “support group”, as previous attempts at establishing support groups had been met with little success - attendance was
low and longevity limited. Thus, the promotion of this program needed to focus not on the “support” aspect, but on the “educational” component of the program. Additionally, it was important to highlight aspects of the program that met unmet needs of the group, such as access to educational resources and alternative forms of physical activity.

Despite reluctance on behalf of residents to participate in previous support group initiatives, the demand appears to exist for educational and supportive care among the general public and those with cancer. For example, one gentleman with heart problems enquired about participating as he was interested in a program that addressed medical management, nutrition, emotional health, physical activity and overall wellbeing. Additionally, approximately 25% of the phone calls received were from patients who were actively receiving chemotherapy treatment. As this program is specifically tailored to those who have completed their cancer treatment, screening participants before allowing sign-up was very important. Tracking this interest from the general public and from those receiving treatment, however, illustrates that a need exists for psychosocial programming in the area.

The program started on January 31st and ran for 6 weeks. The last session was on March 7, and a booster session took place on March 28th. The sessions were held on Saturday mornings as this was thought to fit into people’s work schedules, allowed participants adequate travel time (particularly if weather conditions were a factor), and would not fatigue participants as would sessions during the week. Furthermore, the sun goes down early during the winters in this area and thus residents tend to “hibernate” during the week. Having an activity to get out of the house and go to on a Saturday morning was deemed motivating. The program itself was held in a central, and well known location in Prince George - PGRH; however the location was changed after the first session as more space was required. The facilitator connected with each patient between the first and second sessions.

The facilitator noted the importance of connecting with each participant before the sessions in order to have an idea of issues that participants wanted addressed. As well, it was necessary to allocate time for potential follow-up discussions after the sessions concluded in order to address any crisis issues that may arise during a session. For example, in 4 out of 6 sessions the facilitator had scheduled sessions with participants as many had concerns that they wanted to discuss.

**Institutional Context**

In order for the Cancer Transitions program to be successful, buy-in at the institutional level was vital. Without acceptance by healthcare practitioners, promotion of the program and recruitment of participants is very difficult. Bringing about awareness of the benefits of the program is an important factor in establishing acceptance. For example, chemotherapy nurses have traditionally not engaged with patients about the impact of cancer after their treatment is completed due to their limited contact with them. A program participant’s friend happened to be a chemotherapy nurse in the area and she expressed her appreciation for the program as she had witnessed the improvement in physical ability and emotion health of the participant.

Additionally, the family physicians in Prince George are also part of the larger institutional context. The importance of engaging this group was made evident when the facilitator received a referral from a GP who had heard about the program through one of his patients. As the advertising budget will be smaller during the next round of programming, potential strategies for engaging this group and encouraging patient referrals were discussed. One idea was to promote the program by putting flyers in the GPs mail slots.
While buy-in and involvement of health care professionals is key, so is the ability of the project team to adapt the program to available resources in the community. Locating the resources and personnel for the fitness component of the program was noted as a challenge by the project coordinator due to the limited number of physiotherapists and fitness experts in the area, as well as the limited accessibility of physical activity resources. A great deal of time and effort was dedicated to locating a qualified fitness expert who had knowledge of cancer treatments and experience working with this population. In the end, the choice was determined by the person’s availability and commitment to working as a fitness expert on future projects, their experience working with individuals who have chronic illness, and their personality and ability to motivate. The facilitator assisted the fitness expert with their slide presentations, consulted with them before the sessions to answer questions or offer feedback, and shadowed them in the chemotherapy unit. This mentoring was considered essential to developing this role, as was giving encouragement and feedback throughout the process. The facilitator noted the importance of building relationships with community health care providers and resource professionals, particularly those who offer services that are in short supply.

The scheduling of the topics needed to be flexible in order to accommodate the availability of the health care professionals (dietitian and the GPO). This flexibility was important in order to ensure that professionals were available to present when the topic called for. The presence of a doctor was thought to be a critical component in the sessions as often patients had questions about their treatments or other issues and wanted to speak with a doctor about them. Providing a forum to allow patients the opportunity to ask questions of a doctor in a group appointment setting is a great way to promote health, and a setting that few patients, regardless of where they live, have access to. The facilitator noted that in future sessions a doctor should be present, particularly in the Medical Management session. Payment could perhaps occur through the group doctor visit initiative. The booster session that occurred three weeks after the last scheduled sessions explored two alternative forms of exercise through demonstrations given by specialists as this was a topic that participants had requested.

**Economic Context**

The economic context of sustaining the Cancer Transitions program has to be considered in terms of both the cost of running the program and the cost to participants. In terms of program costs, factors that need consideration are the printing of materials, the human resource requirements needed to run the program twice a year (projected goal) and the ability to retain a dietician and fitness experts in a rural setting. From a patient perspective, costs associated with travel, childcare, taking time off work and the logistical issues of committing to a six week program all need to be taken into account.

**Discussion**

The facilitator commented that the KE-DS Toolkit was extremely helpful in terms of prompting herself to ask the questions of ‘why’ and ‘for what purpose’. While many of the issues highlighted in the Toolkit were addressed and considered, having to articulate what the processes were proved to be very helpful when it came time to report and explain the planning and implementation experiences. Furthermore, having a member of the research team go through the Toolkit and the questions was extremely helpful.

On a local level, the need for supportive cancer care was noted by nursing staff in the chemotherapy unit who noticed that patients were visiting the unit long after therapy was completed in order to maintain a connection to the staff and access the assistance of the social worker. In July 2008, staff solicited patient feedback and recognized that these issues were the result of ending clinical treatment. The need for a supportive cancer care program emerged as a result of both patient and staff concerns over the lack of
psychosocial support in the geographic area – implementing the Transitions program contributed to the documentation and confirmation of the need for psychosocial services in the Northern Health area.

The project team did not appear to have difficulty in recruiting participants to take part in the project, and due to their intimate knowledge of the social and geographical context of the area, tailored the promotion of the initiative effectively. For example, spending a large amount of resources on promotion through local media, and framing the initiative as an educational program rather than a support program was effective. 20% of participants traveled between 100km and 200km to attend the program.

The Transitions program seems to have been well received by the participants as the attendance rate at the sessions was very high despite barriers, such as weather, driving distance and health of participants. It is interesting to note that while the program was “packaged” as an educational program, the indicators illustrate that the psychosocial aspects of the program were effective in improving participants’ quality of life and outlook. The experiential evidence is useful in illustrating the impact of the initiative, as well as the fact that individuals will experience the same program in a multitude of different ways.

In terms of program planning, the recruitment of qualified individuals to lead certain sessions (such as the exercise and nutrition components) was a challenge, and training or preparing these professionals took time.

Social actors and socio-medical dynamics
The social context includes the attitudes and perceptions of the target population, the healthcare professionals and staff. As well, the physical environment must also be considered, both the availability of space for the group to meet, and the geography of the area (communities being widely dispersed). Decision makers setting priorities in site-specific environments need to build consensus about the values that guide their decisions, and must consult with relevant stakeholders in order to ensure that their priorities are being met. The use of the KE-DS model as a conceptual framework can guide priority setting, for it outlines the importance of stakeholder involvement and understanding of the initiative. It is integral that stakeholders accept and be satisfied with the priorities that are mapped out, be in agreement with the allocation of resources, and be involved in the decision making processes that is also enhanced by scientific evidence.

The rural environment presents a challenge to engaging participants that is extremely difficult to overcome. It is therefore important for program planners to be familiar with the area in which the initiative is taking place, and to understand the social context of the participants and the institutional context (such as issues that health care practitioners face around time commitment, availability of experts, etc.). Logistical issues, such as promotional strategies, time of day, room booking, etc. are made that much more difficult when the environment is rural as alternate options are simply restricted. High travel costs for people living outside of Prince George add an additional barrier, and while the option of telemedicine was explored, it was not optimal for this type of program which is optimally presented as a face to face activity. Furthermore, the weather conditions are a factor – the goal is to implement the program twice a year, once in January and once in September. January is a gloomy time of year when people tend to get down and so having something to look forward to might be good for participants, and September is commonly thought of as a time to start new things, so participants might be ready to try something new.

Because of the considerable human resource component, utilizing Canadian Cancer Society volunteers to help with promotion, registration, room bookings, etc. would be beneficial. In terms of involving health care professionals in the sessions, the team discussed having a social worker and dietician to do single sessions. While the option of having a nurse practitioner do the oncology piece was discussed, the facilitator
commented that as participants from this area are inclined to value the expertise of a GPO over a nurse, a GPO will likely be utilized in the future. In a regional perspective, the facilitator noted that it would be beneficial to involve PGRH and the regional clinics to give financially to their base and to assist in advertising. Furthermore, PGRH could potentially assist in defining who is eligible for the program, such as those who have almost completed their treatment. The facilitator also commented that ideally there would be a “champion” of the program at the community level.
BC Cancer Agency, Vancouver Island

Background
The facilitators involved in the Vancouver Island offering of Cancer Transitions noted their awareness of the growing and strengthening voice of cancer survivors regarding the issue of post-treatment follow-up or survivorship care planning and survivorship programs at both the provincial and national levels. There have been a number of national meetings (CPAC), as well as two recent conferences (BCCA 2008, CAPO 2009) on the theme of survivorship research and programs. An ongoing internal provincial review (commissioned by BCCA/PFC) considering the patient and family counseling services is also exploring the literature related to psychosocial services in oncology. An emerging theme is a trend towards a more structured, holistic and psycho-educational approach to support groups than what has traditionally been offered to cancer patients on Vancouver Island. This shift in structure is consistent with patient feedback received over the past few years.

In keeping with this trend towards a structured and holistic approach to cancer support care, the facilitators welcomed the opportunity to be involved in the Cancer Transitions program. The research component was particularly appealing as this would offer the opportunity to examine the impact of the program on participants, as well as to provide a forum for patient feedback regarding what was needed in a survivorship program. It was also helpful that there was an existing and highly positive partnership with the BC Cancer Agency (BCCA) and The Wellness Community, both reputable organizations. The Vancouver Island team was excited about being part of the first pilots of the program in Canada.

Establishing the Need
The two facilitators had heard from many clients over several years of practice that transitioning to life following the end of active treatment can be very challenging. Further evidence came from their involvement in facilitating two focus groups throughout the autumn of 2008. Both of the focus groups involved breast cancer survivors and offered them the opportunity to give feedback on the topic of survivorship care planning. The women’s feedback indicated a great range in experiences and pointed to many gaps in how the system helps women breast cancer survivors with transitions and follow-up care at the end of active treatment.

In addition, one of the facilitators has also run a Life After Cancer group that has been offered a few times a year during the past several years. This group has been offered for women only. The feedback from participants has been that the group has been helpful, a comment that validated the need for transition support. The Life After Cancer Group concentrated on the psychosocial and some informational/educational needs of female survivors.

The aim is to offer the Transitions program four times per year as the program fits with Vancouver Island’s current infrastructure and mandate.

Site Description
The Vancouver Island Centre is one of five full service Cancer Centres of the BC Cancer Agency (BCCA). The centre provides oncology consultations, chemotherapy and radiotherapy treatments for people who live on

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8 http://www.bccancer.bc.ca/RS/VancouverIslandCentre/default.htm
Vancouver Island, and provides a broad range of services including prevention, treatment, screening and supportive care.

The Vancouver Island Centre is an active research clinic contributing to knowledge generation within the facility. Clinical trials are an extremely important aspect of their clinical care and the team is intimately involved in a growing research program.

The Vancouver Island Cancer Centre is located next to the Royal Jubilee Hospital in Victoria, BC. The cancer information notice boards are one source for resources and are located on the first and second floors of the centre. The library is another source, providing pamphlets, books, videos and tapes. Patient and Family Counseling Services offer these counseling, education and support programs for patients, family and friends:

- Brain Tumour Group
- Rehabilitation Counseling
- Counseling Services
- Therapeutic Touch Clinic
- Lung Cancer Group
- Ovarian Cancer Support
- Breast Cancer support group
- Relaxation Program
- Young Women’s Group
- Women with Metastatic Cancer

Additionally, these programs are available for patients and their supporters in Victoria and the surrounding communities:

- Chemo teach
- Gyne Nutrition Session
- Look Good…Feel Better Program
- Lymphoma Leukemia support group
- Myeloma Support Group
- Nutrition for Breast Cancer Patients
- Pain Teach
- Prostate Cancer Support Group
- Prostate Cancer Hormone Therapy information session

Services

The Vancouver Island Centre (VIC) is on the campus of the Royal Jubilee Hospital (RJH). As such, there is access to many of the services available at the hospital.

- Coffee Shop
- Chemotherapy
- Gift Shop
- Interpreters
- Laboratory (RJH)
- Library
- Nutrition Counseling
- Order of the Eastern Star
- Patient and Family Counseling
- Pain & Symptom Management
- Pharmacy
- Psychiatry
- Radiation Therapy
- Support Groups and Education
- Volunteer Driver Program
- Wigs and Head Coverings

The Cancer Transitions program was offered twice through the Vancouver Island Centre, each time with a different facilitator. Round One had a very limited time frame of three weeks in which to market and recruit
participants. This was due to the need to have ethics approval prior to advertise the program start date. The program was primarily promoted through word of mouth, emails, internal flyers, and public service announcements, and an article in the local newspaper that came out the day after the first program began. This helped with recruitment for the second program, as several participants saw the article and called the centre to be added to the wait list. Round two participants also saw flyers that were put in each of the Clinics within the Cancer Centre, in individual doctor’s offices and waiting rooms, and/or heard about the program from Round One participants or other patients.

Round one was held in a conference room within the Vancouver Island Cancer Centre. While it was on site, it was not ideal as the room was small and hot, particularly for exercising. A vegetable or fruit tray was provided during each session.

Round two was held at the YM-YWCA in downtown Victoria. The shift in locations allowed for a balance between sustainability and efficiency, and the centrality of the location served the population better. Most of the sessions were held in a bright, long and narrow room that had an adjoining kitchen. Chairs, flip chart, side tables and laptop/projectors (to show overheads) were brought in. This room is opposite a large and well equipped gym space. The narrowness of the room was a challenge as setting up chairs in a circle was difficult, as well, the acoustics were not ideal and participants sometimes had difficulty hearing one another. A few different setups were tried, such as a lecture style for the medical management session, and this somewhat improved the situation. Other rooms were used in the Y facility depending on the activity for that session. Some patients attended as a result of a referral from health care professionals - one person was referred by their oncologist and a few others from counsellors in Patient and Family Counselling. Promotional material did not go out to family practitioners.

Identifying Stakeholders
Health care practitioners, social workers and patients were all considered stakeholders by the project team.

Population of Interest
The target population for this initiative was English speaking adult cancer patients who are 0-24 months post treatment for any tumour site living in Victoria or within commuting distance.

Both facilitators pre-screened participants for suitability and commitment to a group program. During this 10-20 minute phone call, facilitators also discussed the voluntary research component and reviewed the research inclusion criteria. There were thirteen participants in Round One - twelve women and one man. Attendance was excellent and there were no dropouts. A consistent comment was that people wanted more time for discussion.

Round Two was a larger group with twenty participants – four men and 16 women. Eleven participants had perfect attendance; seven missed one class (i.e. important medical appointment, funeral, work issue, eldercare issue, planned holiday). One person missed the last two sessions due to a pre-planned holiday. One person missed the last three sessions and was considered to have dropped out.

Population Impact
The impact of the Cancer Transitions program was measured through the use of several questionnaires (see page 14 for a list of these measures). The facilitators offered the following experiential evidence based on their own experiences and feedback from participants.
Participants in Round two noted that the sessions seemed rushed at times, and some noted that more time for discussion would have been helpful. The facilitator was occasionally concerned that a small number of people dominated the discussion while others were very quiet. She attempted to draw out quieter members in a number of ways, such as asking direct questions, using the overhead to pose questions, and doing rounds where a question is posed and everyone in the circle has an opportunity to answer. One group member was relieved when a few tears were shed in session three, as she said she felt less alone in her fears compared to in session one when “everyone seemed so together and one person said the idea of death didn’t bother her”. This greater level of emotional openness in the group appeared to be a reflection of the increasing comfort level. People were able to share some very difficult circumstances that occurred at the time of and around their cancer diagnosis, such as the experience of losing others, a challenging marital relationship and competing demands to be the caregiver during treatment. Lastly, participants noted that they had increased their physical activity.

**Social Context**

The social context that the project teams operated within significantly impacted their offering of the program. The facilitators have detailed their experiences by referring to different sessions of each offering.

**Fitness Sessions**

*Round One at the clinic:* The exercise component was facilitated by two different instructors from the YM-YWCA. One instructor (female) led the exercise sessions in round one and was working towards a kinesiology degree. The second instructor (male) filled in when she absent. Both instructors agreed that this was a challenging group to lead as participants’ interest, motivation, fitness levels and health situations were highly variable.

Despite her fitness background, the lead instructor had limited exposure and experience with cancer patients and their exercise needs/limitations. Her exposure to the research literature seemed fairly limited and she did not consult the literature on cancer and exercise; however she closely followed the facilitator’s guidebook (session two) – but the content there is ‘fairly thin’.

The instructors felt quite limited by the physical environment of the clinic: the room was small and very warm. Activities were mainly limited to sitting and standing exercises, such as using exercise bands, as these could be easily transported to the Clinic. A small number of people submitted their exercise logs for feedback - most used their pedometer and it seemed to be a successful motivator to exercise.

*Round Two at the YM-YWCA:* This was a larger group with 20 participants, and therefore both fitness instructors (one male, one female) were involved in leading the exercises. While the fitness instructors were made aware of the range of exercise levels of the participants ahead of time, they expressed that this was a challenging group to lead given their diversity. They felt it was helpful to be at the YM-YWCA (their normal place of work) as it provided many more options for activities. When planning the weekly activities, the instructors asked participants to complete a form indicating their preferences and interests from a menu of possibilities. Activities included the development of a weight training program and instruction in using the treadmill, bicycle and elliptical trainer. During some sessions, the group was split in two and did separate activities in rotation; and during other sessions, participants chose one of a number of activities. Yoga, Pilates, floor exercises, badminton, weight training, and cardio machines were offered. Time in the pool was also an
option; however a lack of interest led to eventually dropping the activity. While very few people regularly completed their exercise logs, a number of people at Session Six noted that they were continuing to use their pedometers and focused on walking more daily.

In order to facilitate a greater understanding of the positive impact of exercise for cancer survivors, the facilitator provided books, articles and additional overheads to the YM-YWCA instructors. Very little of this information (other than the overheads) was utilized in the fitness experts presentations, and the session did not appear to engage participants. For example, one participant said “they were too much like cheerleaders; I could see people turning off”. Based on this experience, the facilitators have decided to alter the delivery of information at future sessions. The facilitators themselves will provide the overview of the literature, and the fitness instructors will provide exercise leadership and possibly participate as guest speakers, such as when a kinesiology specialist would be relevant.

**Nutrition Session**

Vancouver Island Cancer Centre has limited access to specialized oncology nutrition resources – i.e. there are three part-time nutritionists and partly because of resource limitations, their focus has been on high risk cancer patients during treatment rather than on addressing survivorship issues.

The nutrition session went very well and was positively evaluated by both sets of participants. The nutritionist guest speaker was both dynamic and practical in her presentation of information. While she did not follow the workbook materials closely, her key messages were consistent with those given in the workbook, with a few exceptions such as the emphasis on eating organic and American information that does not apply to Canadians. There are high costs associated with eating organic, fresh foods and – in contrast to the workbook materials provided – our speaker de-emphasized the need for consuming organic foods. Instead she noted that washing fruits and vegetables well in warm water would get rid of pesticides.

In general, the participants were highly literate and had conducted their own research on nutrition related to their particular cancers. They were “hungry” for good and credible information, as they had read a great deal that was contradictory - it was therefore essential that the nutritionist had the latest information to draw from when responding to participants’ questions and concerns. The participants appeared satisfied with her practical and informed approach.

**Medical Management Session**

The medical management session also went well, with the same nurse educator presenting in both rounds. The information from the facilitator’s guide was clearly presented using the outline and overheads provided. In round two, many participants took the opportunity to ask pertinent questions of the nurse educator and found this session helpful.

**Booster Session**

In Round One, participants did not want an exercise component at the booster session and instead requested more discussion time with a focus on visualization and goal setting, while participants in Round Two wanted the exercise component included in the booster session. Participants from both rounds planned pot lucks and check-in/discussion times with each other.

**Economic Context**

The issue of funding emerged, as sustaining the program is a concern. Ideas discussed were offering the program as stand-alone sessions; however facilitators noted that the support component would then be lost.
Discussion

According to project facilitators, for the most part the Transition program is a culturally and geographically appropriate program for those living in Victoria. The program would benefit from an addition of Canadian content. Furthermore, the program complements the programs already offered at the Vancouver Island Cancer Centre and contributes to continuity of care after patients have completed their treatment.

In terms of promoting the program, three weeks is not a sufficient amount of time - the facilitators recommend 5-6 weeks as a more realistic amount of lead time in this urban context. While newspapers are effective in raising the program’s profile and awareness over the long term, they should not be relied on as the sole promotional tool. Rather, word of mouth and flyers in the Clinics and in Radiation Therapy tended to work best for promoting the program, as did direct referrals from oncologists, counsellors and nurses. Free public service announcements (PSA's) in local newspapers are not that visible and do not tend to lead to referrals.

Screening participants is very important and planners must allot time for a 10-20 minute phone call with each prospective participant. The facilitator of Round One spoke with many individuals who were interested but were either not eligible or appropriate for this type of group. Round One operated with 13 participants. The facilitator of Round two screened approximately 35 individuals and ended up with 20 participants.

Having a group size of 19 participants is challenging – facilitators recommend 15 participants as a maximum. As well, facilitators wondered whether the “appropriate” people were being targeted, as group participants were generally well-educated and highly resourceful.

In terms of the content, the facilitators believed that the nutrition component was very good. They noted that that psychosocial component could be more focused, and that the program would benefit from being “Canadianized” with more relevant content.

The facilitators noted that the KE-DS Model provided a useful framework for planning, implementing and evaluating the Cancer Transitions pilot program. While many of the questions had already been considered by the facilitators, it was helpful to go through the model systematically and the model did provide additional questions and raised additional issues for consideration. The KE-DS helped them “step back” from the planning and examine the clinic and community contexts, as well as the feedback and participation within the two groups.
Hope and Cope, Montreal

Background
In the area of cancer patient survivorship, the Hope and Cope team was interested in the program proposed by The Wellness Community, “Cancer Transitions”. To the team, it made intuitive sense to pilot a developed course.

Establishing the Need
The participants who have recently completed their treatment expressed to the facilitators that post treatment support and assistance is uncommon. While there are several support groups and programs for site specific cancers, there are few survivorship programs. In the last 2 years a nurse clinician had given a short program on survivorship for women with breast cancer who have completed treatment, but with her departure no further survivorship courses were planned.

As larger numbers of persons are surviving cancer, it has become an objective of Hope and Cope to serve this population well and meet their needs for information, support and well being.

Site Description
Hope and Cope is a peer support volunteer based oncolgy support with more than 300 volunteers. It has been housed at the Jewish General hospital which is a McGill–affiliated centre, and has recently opened a Wellness Centre. Hope & Cope is a beacon to anyone touched by cancer. Hope and Cope is recognized as a leader in peer-based psychosocial care and contribute new knowledge and research to this evolving field.

Hope and Cope is a strong member and supporter of the clinical care teams at the Jewish General Hospital's Segal Cancer Centre and are connected to a network of community and academic organizations to remain at the forefront of supportive cancer care. Guided by professional staff, cancer-experienced volunteers provide psychosocial support and practical resources that help patients regain a sense of control and well-being, reduce isolation and restore hope. Easily accessible and open to all, Hope & Cope is funded by the community and is located at the Jewish General Hospital's Segal Cancer Centre and the JGH Hope & Cope Wellness Centre. Founded in 1981 by Sheila Kussner, O.C., O.Q., Hope & Cope is comprised of close to 300 volunteers, managed by a professional staff. Services are provided free of charge from two locations - the home base at the Jewish General Hospital, and the recently established JGH Hope & Cope Wellness Centre (Lou's House) at 4635 Côte Ste. Catherine Road. Hope & Cope is financially autonomous, relying on the support of individual philanthropists, foundations, the corporate sector and the general public.

The Objectives of Hope & Cope:

- To provide a system of peer support for patients and family members, using the expertise of cancer-experienced volunteers.

- To provide a range of specialized services which respond to informational, social and psychological needs. These programs are offered at any point along the cancer continuum, including diagnosis, treatment, survivorship, recurrence and bereavement.

http://www.jgh.ca/en/HopeCope?mid=ctl00_LeftMenu_ctl00_TheMenu-menultem000
• To recruit, train, supervise, educate and support volunteers, as well as recognize and highlight their efforts.

• To educate the community and the health care team about the psychosocial aspects of a cancer diagnosis and the benefits of support systems such as Hope & Cope.

• To conduct research and critical evaluation that underscores and promotes the value of oncology volunteer programs in general and Hope & Cope in particular.

From its inception over 30 years ago, Hope and Cope had a strong research focus as part of its mandate and philosophy. Several research studies have been published in peer reviewed journals as a result of their research into volunteerism and psychosocial support.

Among the many attendees at the JGH Hope & Cope Wellness Centre (TWC) are many participants who have completed their cancer treatment. The Wellness Centre is a freestanding building near the Jewish General Hospital in Montreal that houses a variety of activities such as onsite exercise and cooking in a learning-equipped kitchen. The Centre holds many support groups, yoga classes and art therapy, among others. It is open to all cancer patients in the Montreal area and surroundings although due to travel constraints the majority of the participants are from Montreal.

Cancer Transitions
Hope and Cope has a dedicated space for the Cancer Transitions sessions, including room to exercise. Saturdays was chosen for the program since weekend traffic is lighter in the city and parking is easier. The sessions ran from 10 am and ended with lunch.

The Cancer Transitions program required:
• A facilitator. One of the social workers on staff at Hope & Cope was selected for her interest in teaching and patient education. She was relieved of some of her responsibilities to allow for this new role.

• A nurse experienced in coordinating research studies in psychosocial care was hired to act as study manager. She was present at each session, and monitored the distribution and follow-up of questionnaires.

• Experts were invited to speak about specific topics in the program (e.g. nutrition, medical management) or lead specific activities (e.g. exercise specialist).

• The exercise specialist was a staff person at the Wellness Centre working on his Masters degree in exercise physiology at Concordia University. He already had a continuing presence at Hope & Cope, and participated at each session.

• The medical portion was presented by a doctor and a nurse clinician from the Jewish General Hospital oncology clinic, which is peripherally involved with Wellness Centre and located nearby.

• The Oncology clinicians were very interested in the program and felt that it could be useful for the patients who had completed treatment. The team noted that few family doctors received referrals from their patients’ treating oncologists.
• Having 2 facilitators for the psycho-social sessions including one with a survivor’s perspective brought an extra dimension to talk during the sessions.

Marketing and Recruitment
The Hope and Cope team sent information on the course via their email list to people who had registered with Hope and Cope and who were post-treatment. The team found that word of mouth was effective as volunteers and staff spoke to potential participants, and participants to each other. They did not need outside advertising via newspaper or radio as appeal posters on bulletin boards and internal advertising in the hospital setting sufficed for their community of interest.

Identifying Stakeholders
The stakeholder groups consist of patients and their families, volunteers, oncology health care professionals and community groups who focus on the well being of persons with cancer.

Population of Interest
The team targeted adult cancer patients from the Montreal area who could speak English. There were 20-22 participants who were Bilingual and English speaking, males and females.

Population Impact
The 6 week program was successful as measured by attendance over time, participation and evaluation forms of both participants and staff. The results of the questionnaires will illustrate the impact of the program on reductions in distress, increases in healthy behavior, such as diet and exercise and functional ability. The team knows that relaxation is linked to good psychosocial outcomes and they are therefore interested in the frequency of practice.

Because the Wellness Centre has an onsite exercise program, many of the participants were familiar with the exercises suggested by the program. Nonetheless, the participants were happy to exercise and the trainer was very enthusiastic. In the future, the team may decide to modify the exercise component given the fitness level of the participants and other available programs. Some participants initially thought they wouldn’t be able to participate in the exercises and were pleased to note how they improved over the sessions. The team may mix the exercise session up by bringing in programs that are available at the centre such as– yoga, tai chi or dance.

The psycho-social program was well received as one of the facilitators teaches a coping skills program, “Think Smart, Live Well,” on a regular basis. Participants welcomed the opportunity to discuss their emotions. At the Booster session participants continued to focus on communication.

The nutrition session was interactive, where the nutritionist prepared and cooked the food before the group and then the meal was shared by all. Lunch became an informal time to make connections, share information and consolidate knowledge. Adequate time for a lunch break was important as participants used that time to ask and answer others more personal questions, similar to a Dr Ruth’ session. There were, however, several suggestions made by the nutritionist who works part–time with Hope & Cope, particularly centered on not recommending brand name products, and recommending only snacks that are made of no processed ingredients.
Social Context
Hope & Cope is known as a community service as well as a service associated with the Jewish General Hospital. At present, efforts are underway to broaden that perception to include all cancer patients in Montreal who are free to join the Wellness Centre.

Patients depend on their physician’s word, and thus the team is hoping to learn how best to include physicians more extensively in their programs. The team believes that the Cancer Transitions program is an excellent addition to their work with cancer survivors, and they plan to offer it on a regular basis, while changing the content in small ways to fit better within the Canadian context. The team would appreciate the development of a summary information sheet to circulate to patients, care givers, staff and physicians.

Economic Context
Hope & Cope is a community based program supported entirely by donations - fundraising is an integral part of its activities. The Board of governors looks at the evaluation of programs offered by Hope & Cope in terms of attendance and costs.

The team has space at the free-standing Wellness Centre for the Cancer Transitions program. Many of the staff contributed to the program during their own time or on work time, and other speakers are paid an honorarium. Hope & Cope covered costs for parking for each participant; however, since the program ran on Saturdays when traffic is light and parking much easier, future payments for parking will likely be cancelled. The major costs for future program delivery are primarily those associated with recruitment, advertising and the purchase of the course materials. A one-time major cost prior to further delivery will be the costs of translating and printing all course material into French.

Discussion
According to project facilitators, the Transition program was easy to implement within the Hope and Cope site due to extant facilities. There are both an established kitchen and exercise rooms.

There was discussion that the program would benefit from an addition of Canadian content, and there were suggestions to revise some of the nutrition material. It was felt that the exercise section could be expanded to sample programs already available at the centre such as yoga, tai chi and dance. There is a need to have the materials translated into French if it is to be used with the greater local community.
Commitment to Supportive Cancer Care: The BCSCF Breast Cancer Recovery Group Program, Calgary Alberta

Background
The Breast Cancer Supportive Care Foundation (BCSCF)\(^\text{10}\) in Calgary, Alberta was established in 2003 as a not-for-profit community based organization that provides medical care and support to breast cancer patients and their families throughout their cancer journey as they transition from illness to healing and health. BCSCF has linkages with community health care providers and resources, the Calgary Health Region Breast Health Program, the Tom Baker Cancer Centre and other relevant medical initiatives and community based organizations in Calgary. Medical services provided by the physicians are covered by fee for service through Alberta Health Care. Additional programs and services are supported by grants, donors and fund-raising initiatives in the local community.

The mission of the Breast Cancer Supportive Care Foundation is to enable breast cancer patients to thrive from diagnosis through treatment and beyond. This mission serves a greater vision, to lead in the design and delivery of an innovative model of care for breast cancer patients. Where the existing healthcare system focuses on the acute cancer survival period, BCSCF focuses beyond treatment to survivorship and to a model of care called “thrivorship”, assisting patients to return to full and vibrant lives in their families and communities. BCSCF does this by offering multidisciplinary individual patient services and innovative group recovery programs while working to expand the impact of this approach in the broader community.

Establishing the Need
The Breast Cancer Supportive Care Foundation’s mission grew out of feedback from a breast cancer support group (May 2002) where the need for a new model of care was identified. BCSCF medical staff recognized the void that patients enter post treatment and the benefit of developing a change management course that provided a sound framework for assisting breast cancer patients who have completed treatment transition from illness to optimal health and wellness. The principals of BCSCF further identified the survivorship issues of breast cancer patients in a patient-centered approach through surveys, focus groups, individual patient encounters and course evaluations and feedback from six Breast Cancer Recovery groups offered by Breast Cancer Supportive Care Foundation during 2007 through 2009.

From this extensive feedback and personal and professional experience BCSCF staff identified the need for an integrated holistic survivorship course that would increase capacity for provision of high quality and consistent survivorship care.

The goal was to deliver an intervention that combined medical and nutritional education, an exercise program, stress management techniques, behavioral training, and psychosocial group support. Due to a lack of resources in survivorship care both locally and nationally to assist patients and their health care providers in the survivorship period BCSCF staff determined that developing course materials would optimize programming for their patients. Over the course of 2007-2009, they worked with a curriculum development team to create a standardized 12 week course curriculum with a framework that could be restructured into a format that could be delivered through interactive web-based modules so as to increase accessibility to patients who lived in more remote geographical settings. The 12 module program developed is foundational to addressing survivorship issues of most cancers and is designed such that only module 4, which is cancer site

\(^{10}\) http://www.breastcancersupportivecare.com/
specific and deals with physical side effects of treatment, would need to be modified according to specific side effects of other cancers.

There is a well identified set of Principal PI’s who have been involved in the development of this program and related curriculum, including:

- *Picking up the Pieces: Moving Forward after Cancer*, (Sherri Magee and Kathy Scalzo, 2006)
- *Bridging Self-Care and Health Care*, (Carol Malec et al. 2000)

**Site Specific Program Description**

The Breast Cancer Recovery Group Program developed through this process is a survivorship change management course consisting of three hour sessions once a week for 12 weeks with ten participants who have completed acute breast cancer treatment. Each group is co-facilitated by a physician with specialized breast cancer skills and a psychologist with specialized knowledge relating to breast cancer.

**Program Description**

**LAYING OUT THE PIECES:**
Week 1: Discovering a New Normal
Week 2: Designing a Healing Plan

**RECOVERING A SENSE OF SELF AND SELF CONTROL:**
Week 3: Physical Wellness - Managing Fatigue and Energy
Week 4: Physical Wellness - Managing Side Effects
Week 5: Emotional Wellness - Managing Emotions
Week 6: Emotional Wellness - Managing Loss and Grief
Week 7: Social Wellness - Rediscovering Yourself
Week 8: Social Wellness – Exploring Relationships
Week 9: Spiritual Wellness – Searching Within

**RECOVERING A SENSE OF MEANING**
Week 10: Healing Plan – Putting it all Together
Week 11: Meaning Making

**RECOVERING A SENSE OF FUTURE**
Week 12: Integrating and Celebrating

A multidisciplinary team of health care professionals has developed the materials used in the curriculum for this project. The curriculum has expanded to incorporate both feedback from focus groups and from the participants of the seven pilot sessions. The program addresses physical, emotional, mental, social and spiritual wellness and now incorporates self care, physical activity, nutrition and stress management as they relate to the weekly theme. The Participant Guidebook is complemented by the accompanying course textbook, ‘Picking up the Pieces: Moving Forward after Cancer’ by Sherri Magee and Kathy Sclazo.

The program is designed to be iterative and developmental; for example exploration of fear of recurrence in the emotional wellness module includes medical instruction, self care strategies, physical activity, nutritional information and stress management techniques which together are implemented in a Healing Plan with an integrated approach. The program starts by addressing physical wellness then progresses to explore emotional, mental, social and spiritual wellness. The self care, physical activity, nutrition and stress management components relate to the weekly themes and are also threaded through the twelve weeks and
integrated as the course progresses. Change management strategies and monitoring with a Wellness Passport are used to optimize implementation of the Healing Plan.

At this time the program is run in a dedicated room designed to be welcoming, which contains a sink, fridge, and comfortable couches, around which 12 people just fit. Water, tea and coffee and a healthy snack are provided. There is room for a projector and screen for the session slides and the space allows participants to move a bit around for break out groups, support exercises and hugs etc. Opportunity is given for participants to share their email addresses.

**Identifying Stakeholders**
The stakeholders include the BCSCF multi-disciplinary team of family physicians, gynecologist, psychiatrists, psychologists and nurses, who provide medical care in navigation and transitioning roles for breast cancer patients and family members. They liaise with the Tom Baker Oncology team stakeholders as well as community health care providers, referring physicians and local hospitals. Women with breast cancer in Calgary, as stakeholders, have contributed through course evaluations and feedback from six previous Women’s Breast Cancer Recovery Groups, offered through Breast Cancer Supportive Care. Beyond this, individual staff, volunteers and contractors have also contributed to this project.

**Population of Interest**
Currently each Breast Cancer Recovery Group consists of ten female participants plus the two facilitators. This strategy maximizes the benefit for expense of the program and makes it more accessible to the many potential participants available. Program costs ($2000 per patient) are covered by donations to the BCSCF.

This cohort is developed via invitations sent to breast cancer patients who are identified from the Breast Cancer Supportive Care Foundation patient database. Prior to entering the program, a full assessment of breast cancer patients is completed by one of the team’s family practitioners trained in psycho-social oncology. A minimum screening of one extended doctor’s visit is completed. This allows the program team to tailor the group, and to select for group dynamic and similar ages (i.e generally 20 – 45 yo and 45 – 65 yo women are placed together). Patients are identified based on availability and commitment to attend the group. Patients are asked to commit to the totality of the program. The program is highly regarded and has many people waiting to take sessions. Some participants travel to come to the sessions, but for the most part participants are residents of Calgary. Their sessions typically have had 100% attendance. Participation is limited to non-metastatic, female breast cancer survivors who range in age from their 20’s to 60’s.

The chosen participants are therefore a very specific population, as a great deal of thought goes into a very selective choice of highly motivated breast cancer patients. The current group (2009) ranges in age from 42 to 55, but earlier groups have had an age range from 33 to 64. There does not tend to be significant interest from patients who are in their mid to late 70’s.

**Population Impact**
The project team gathered both qualitative and quantitative data by tracking participants’ use of their pedometer and their journal responses to five structured questions which stimulate reflection on physical, emotional, mental, social and spiritual wellness. Much of the writing the participants do, however, is personal and remains private.

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11 The program requires a high degree of literacy. There are 20-30 pages per session to read in the package plus a textbook. As well there is a journaling component, an analytical thought component (attentive walking journal), and expressive component. Participants benefit by being comfortable with the use of email and the internet.
The program has been developed to incorporate change management components, to develop an integrated ‘healing plan’ and to engage the participants to actively bridge their health care with self-care. The goal is to return control to the patient after what may have been a disempowering experience within the medical system. Participants are encouraged to develop a self-tailored support team to assist them in moving back into life (a corollary with the treatment team) that may include psychologist, clergy, physiotherapist, nutritionist, and/or individual physical activity programs etc., from resources available in the greater community. This is designed to facilitate a shift in the ‘patient role’ by moving participants into a self-management role characteristic of chronic disease management. The goal is to give participants the terminology and tools for developing a therapeutic direction and for knowing when medical intervention is necessary. Empowerment, problem solving and problem ownership are key outcomes. Return-to-work plans are addressed outside the program. Many participants are either not yet returned to work or in a graduated return to work program.

Psychosocial support is a key focus of the strongly guided curriculum, with provision for assistance outside the program time for patients who exhibit signs of distress. The program starts generally, with low stress topics and is designed for pivotal shifts to occur at three, six, and ten week points. For example, the first two weeks of the program lays out the pieces of the recovery process and Healing Plan. In Week 3, physical wellness, particularly how to manage fatigue, is addressed. This is a non-threatening set of information and allows participants to ease into the program; to in fact ‘bond over basics’ as all participants experience fatigue. This commonality of experience is reiterated through the first weeks of the session.

Sessions are guided, safe and facilitated. Each of the participants completes a confidentiality statement. The space is designed as a safe space and ritual elements (lighting a candle, group de-stress times, development of a Memory box in which participants collect items that symbolize losses) are incorporated. Bonds between participants and program staff are developed before delving too deeply into intensely emotional issues. The expertise of the facilitators and the number of pilots already undertaken define this as a safe and authoritatively guided process. There are always psychological supports in place as a safety net, and the nature of the in-house, dedicated team allows for immediate attention to distress signals from participants.

Along with the course textbook and their Participant Guidebook binder, participants are given a Wellness Passport and a pedometer as take-aways. The course binder contains both reading materials and space for reflection about structured question sets. All materials in the binder are tied to the instructor-presented PowerPoint presentations that are part of each session. This program is designed to be very time intensive outside the 3 hour session: there is ‘home work’ (which takes between 1-3 hours per week) and participants are expected to develop a symbolic artwork or performance piece for presentation in the latter half of the program. A high degree of literacy is required as the course has an extensive reading requirement both pre-program and during the program, journaling components and a range of intense self-discovery exercises.

As well as offering psychosocial support, the program has a well developed exercise component aimed at encouraging participant adoption of physical activity. The core program is supplemented by an exercise component completed outside the session time. Walking was chosen because it can be done separately from the program time, allows for different fitness levels, abilities and preferences, and does not require expensive special gear or specialized expertise. This exercise choice is based on research evidence that shows that

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12 The patient role has been changing to focus on self-management and records maintenance. Patient and provider expectations regarding the patient role often come into conflict.

13 Because of the longer program period, re-occurrence vs. progression of disease occurring in one or more participants is a possibility.
walking briskly 30 minutes a day for six days a week, reduces the risk of recurrence of breast cancer up to 50%.
As well, there is data that a sedentary lifestyle interrupted by intensive irregular fitness sessions is not as beneficial a practice as intermittent exercise throughout each day. Walking is an ideal baseline exercise, because once participants return to work, they can make the walk part of their regular daily routine. This exercise component is designed to be maintained outside the program so facilitates the goal of behavior change to a constant and consistency of activity.

In the initial sessions, walking for twenty minutes a day is set up as a reflective tool. Participants talk in group about walking, track how much they are walking and at the same time discuss it’s role in stress management and nutrition. During the second and third month, there is a developmental shift from reflective walking 20 minutes per day to adding brisk walking after the Attentive Walking exercise with the goal of walking 30 minutes a day, six days a week and eventually clocking 10,000 steps daily on their pedometers.

Social Context

Health System
In Alberta the provincial system is in the process of change. BCSCF as a community foundation is not directly impacted by the on-going changes in the provincial reorganization of the medical system. The BCSCF programs fit into the wellness model and complement the services provided by the surgeons and nurse navigators of the Calgary Regional Breast Health Program as well as the services available through the Tom Baker Cancer Centre. All patients access BCSCF services with a physician referral and medical colleagues who refer their patients and are very positive about the care received. This may be in part due to the acceptance of GP specialists in the health care environment (nurse practitioners are a very accepted model too). The majority of referrals are received from family physicians but surgeons and oncologists also refer patients to BCSCF. The goal of BCSCF is to transition patients back to their family physicians and to be available for consultation to both physicians and patients should new concerns arise.

The BCSCF has three main programs including the multidisciplinary individualized medical care program, the Breast Cancer Recovery Group program and the newly developed Healthy Living After Breast Cancer (HLABC) program. In the HLABC program, a chronic disease management nurse specialist meets with patients who have finished treatment for a 90 minute individual consultation to complete a Wellness Assessment and together develop a Wellness Plan. Patients are offered follow up visits to review progress as needed. BCSCF strives to link patients to the services of other community based organizations such as the Canadian Cancer Society and Wellspring14.

BCSCF is well-established in the community, with the lead doctor being highly regarded and well-connected within the local medical community, with upper levels of administration and management in the health care system. As well, this doctor has contacts in the local university.
BCSCF benefits from being firmly embedded in the medical community and has access to medical records in the Health Region and Cancer Centre. This facilitates optimal information exchange and continuity of patient care.

The adjunct walking program is facilitated by the fact that Calgary has many places to walk: there is a walking route in malls and at local sports centre and it is possible to walk throughout the day in the ‘+15’, which is a

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14 Wellspring (Calgary) is a community-based, endowment and donation based cancer support program, run by volunteers, that offers programs and services free of charge “to individuals and caregivers who are experiencing any type of cancer. With registration, a Wellspring member can participate in expressive and movement programs, individual and group support and week-end workshops for as long as help is needed.” Annual operating costs for the centre are approximately $450,000. http://www.wellspringcalgary.com/
raised route between buildings that is protected from weather. Local exercise related businesses have walking and running groups for breast cancer survivors, and this choice of exercise component also taps into the package of focused fundraising walks and runs for breast cancer survivors and their supporters. Participants, who are also given the leeway to do stretching and yoga, have access to many dedicated programs at Tom Baker, and community-based cancer support programs like the local Wellspring\textsuperscript{15}, as well as at the local YWCA. Calgary, being an urban centre, also has many public gyms and exercise venues available.

**Economic Context**

*Provincial context*

Medical services provided by the physicians are covered by fee for service through Alberta Health Care. BCSCF also receives funding for a consultant psychiatrist and therapist through the Alberta Health Services Shared Mental Program. Several physicians are members of a Primary Care Network which funds the Chronic Disease Management nurse. Additional programs and services are supported by grants, donors and fund-raising initiatives in the local community.

*Local context*

Calgary is an affluent urban centre. The Foothills Hospital is a large hospital complex with a well-established Cancer care program at the Tom Baker Centre which includes a well-funded breast cancer program. BCSCF benefits from being located on site at the Foothills Medical Centre, where space is at a premium. Their offices and clinic rooms are housed in one of the on-site towers. BCSCF and other non-profit supportive care programs like Wellspring and the Canadian Cancer Society are also well supported by the community through numerous established fundraising events and grassroots support.

Direct costs to the patients would be time, travel and childcare costs. The time commitment for this program is substantial, and courses are run on a weekday in the morning. There is also the commitment to do the homework component (approximately 3 hours per week), and the additional walking component (20-30 minutes per day).

**Discussion**

The Breast Cancer Recovery Group Program has been designed as a multidimensional and integrated process with weaving of themes through the core threads. As participants progress through the program, they build on known information iteratively. As well, the program allows for opportunities for patients to build ownership and involvement in their recovery process, for example patients might decide to supplement the program curriculum by informal extensions like sharing recipes and bringing meals to the meetings. The course outcomes have been enhanced by the presence of the program facilitator who is a psychologist who has individual and group experience in bereavement programs. The program doctors have specialized oncology training, and extensive experience with medical outreach and collaborative health teams.

The recommended optimal start date which considers the participants’ readiness to engage in the program and participant selection based on known data on physical issues characteristic to breast cancer patients finishing treatment (e.g. fatigued and emotionally drained), feedback from previous pilot sessions and a psychosocial understanding of bereavement patterning (Malec et al: 2000) ensures that the patient can engage

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\textsuperscript{15} Wellspring (Calgary) is a community-based, endowment and donation based cancer support program, run by volunteers, that offers programs and services free of charge “to individuals and caregivers who are experiencing any type of cancer. With registration, a Wellspring member can participate in expressive and movement programs, individual and group support and weekend workshops for as long as help is needed.” Annual operating costs for the centre are approximately $450,000. http://www.wellspringcalgary.com/
This allows the program team to tailor the group, and to select for group dynamic. Patients are identified based on availability and commitment to attend the group. Patients are asked to commit to the totality of the program. The program is highly regarded and has many people waiting to take sessions. Some participants travel to come to the sessions, but for the most part participants are residents of Calgary. Their sessions typically have had 100% attendance. This is a very engaged and committed cohort of patients, who are aware that the curriculum is evolving, that their feedback will enhance the program for the next generation of patients, and that this is a very intense experience. During the program very deep bonds are created, as this is a highly psycho-supportive, safe space to explore personal issues and change management.

Currently, the curriculum is designed to benefit breast cancer patients living in urban centres in a program of patient support. However, as the project moves into future stages of development, material can be restructured into a format that can be delivered through interactive web-based modules that could serve the needs of participants who live in remote centres or who speak English as a second language. Other long-term patient objectives would be to adapt parts of the curriculum to transfer resources for other specific cancer target groups (e.g. ovarian). The 12 module program developed is foundational to addressing survivorship issues of most cancers and is designed such that only module 4, which is cancer site specific and deals with physical side effects of treatment, would need to be modified according to specific side effects of other cancers.

The BCSCF Breast Cancer Recovery Group program Facilitator Guidebook, together with appropriate facilitator training, will enhance and extend health professionals’ expertise in a compassionate person-centered model of care to provide immediate benefit to participants from various health disciplines including nurses, health educators, physicians, counselors, oncologists, psychologists, and dieticians. Interestingly, an ‘unintended’ impact of the BCSCF course is the positive impact it has on the health care professionals delivering supportive cancer care programs.
Conclusions: Further Exploration of the KE-DS Toolkit

The Cancer Transitions program\textsuperscript{16} has a set curriculum and outlines the personnel requirements and measures that each project team is to utilize. However, as each project team is operating within very different social and geographical contexts, their experiences of implementing the Cancer Transitions program are diverse. Used as a retrospective activity, the standardized Knowledge Exchange – Decision Support Toolkit allows for the organization of each project team’s experiences into common themes. This allows for a focused understanding of the experiences of each team, while at the same time allowing for the richness of each team’s experiences to remain front and centre and not be simplified into quantitative measures. Within this approach, the unique characteristics and details are the data and they convey the process of planning and implementation. In the end, attention to these processes will potentially lead to a deeper understanding of the challenges and supports that the project managers experienced when implementing the Cancer Transitions program in Canadian settings. In order to facilitate the exchange of knowledge between researchers, project teams and health care practitioners, a greater understanding of these processes may lead to greater utilization of research evidence, more effective collaborations and in the end, an increased understanding of the efficacy, feasibility and impact of survivorship programs on patients and their families.

As it stands, research findings are usually presented devoid of context, i.e. under controlled conditions, and usually reported as “absolute” or “relative” patient outcomes. The KE-DS Toolkit integrates the impact of the social context with the epidemiological, economic and system variables to explain implications for patients and families.

The Social Context

The retrospective accounts of the project teams illustrate that the environment in which they were operating significantly impacted the manner in which they were able to plan and implement the Cancer Transitions program. For example, the Northern Health project team operated within a rural environment in which communities are separated by large geographic spaces, weather conditions are extreme, and the pool of qualified health personnel to draw from is limited. Furthermore, the program was implemented through the Prince George hospital rather than a specialized cancer centre. These circumstances affected the promotion of the program, the buy-in of General Practitioners at the institutional level and the ability of patients living outside the Prince George area to participate. Working with these barriers, the project team was able to successfully plan and implement the program using strategies developed specifically to meet the needs of their rural environment.

The Northern Health team’s experience in planning and implementing the program contrasted considerably with the Hope and Cope team in Montreal. As an urban centre, Montreal serves a diverse population living within its borders and has a large pool of professional health care providers to draw from. Hope and Cope is a well established organization that has been in operation for over 25 years, and is therefore well known and experienced in offering psycho-social support. The project team at Hope and Cope did not experience constraints of the same magnitude associated with recruiting qualified individuals to speak or space constraints, nor did they have to spend as large a portion of their funds on project promotion. They noted, however, that in the future a major cost will be the translating of project materials into French, an issue that highlights the important issue of language in the Canadian context. Operating in a medium sized city (Victoria) and through the BC Cancer Agency, the Vancouver Island team still met challenges associated with recruiting a qualified exercise specialist with a background in working with cancer patients.

\textsuperscript{16} http://www.thewellnesscommunity.org/mm/Treatment-Ends/cancertransitions.aspx
The unforeseen costs, both financial and time wise, are areas that prospective project teams will benefit from attending to. The Vancouver Island team noted that because they were required to wait until the Research Ethics Board had approved their project before they could start promoting the project, they had a very limited time to promote the program. As well, the screening of prospective participants took substantial time and must be factored in to budget allowances. Northern Health noted that the facilitator spent a great deal of time preparing and talking with the fitness expert.

Finally, the expectations both on behalf of patients and of patients by the program team regarding time commitment varied depending on location. For those in the BCSCF program (Calgary), there is a considerable amount of reading required, and so a time commitment outside of the sessions must be made by participants to get the full benefit of the program. In the Northern Health group, travel to and from the sessions was a factor, with some members driving 200km to attend. Furthermore, promoting the program so that it peaks the interest of the potential participants was very important, as the Northern Health Team noted that traditional support groups have not been successful and that people wanted a more educational focused program.

In conclusion, the incorporation of the KE-DS approach into the daily planning activities will facilitate an evidence-based approach to program planning and implementation. Used as a retrospective activity, it can assist project teams in highlighting areas that worked well, and those that need further attention. The information gathered through the use of the Toolkit will ultimately assist the project team in organizing their planning, implementation and reporting processes, and will assist prospective project teams by highlighting barriers and supports relevant to the social context within which they operate, in addition to identifying the research evidence pertinent to their work.
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