

# A Primary Care Initiative for Cancer Survivorship: A Case Study of Cancer in Obese Men

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## Abstract

**Background:** Men in rural and northern areas of Canada experience considerable challenges in health care access for chronic conditions such as obesity, type 2 diabetes (T2D), and cancer. Obese men (body mass index/BMI  $\geq 30$  kg/m<sup>2</sup>) in rural/remote northern British Columbia (BC) experience poorer health outcomes due to cancer risk compared to other men elsewhere in urban Canada.

**Context:** Challenges faced by men who develop cancer as a complication of being obese are paramount in terms of primary care treatment of their cancers. Oftentimes cancer treatment is multi-modal and complex. Models of shared care have been proposed to provide coordinated survivorship care to the growing population of rural male cancer patients suffering from obesity and the Metabolic Syndrome (MetS).

## Methods:

**Objectives:** The *main* objective of the study was to examine the type of cancer care programs that may have focused on men with cancer in northern British Columbia (BC). A *secondary* objective is to identify challenges in care experienced by men with cancer during their transition from in-hospital care back to their home communities.

**Population:** We conducted a comprehensive literature review and a qualitative focus group interview with primary care physicians (PCPs), oncologists ( $n=8$ ), and a convenience sample of male cancer patients ( $n=6$ ) who have underlying obesity and Metabolic Syndrome (MetS). We examined the types of cancer care programs that may have targeted such men. We further identified challenges experienced by male cancer patients while transitioning back to their home communities.

**Results:** The focus group results outlined themes speaking to a comprehensive shared care model that goes beyond surveillance of cancer recurrence in men with obesity.

**Conclusion:** A shared survivorship care plan or model integrates collaboration among specialists in clinical decision making and best practice for treatment of cancer in obese men.

**Keywords:** men's health, primary care, cancer survivorship, obesity, patient-oriented care, focus group, knowledge translation.

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## Introduction

Shared survivorship care plan (SCP) is the joint participation of primary care professionals (PCPs) and specialist physicians in the planned delivery of care for people with chronic conditions (such as cancer), underpinned by enhanced information exchange, such as through survivorship care plans, which are over and above routine discharge and referral notices.<sup>1</sup> Survivorship care plans act as mechanisms to improve the coordination of care for cancer survivors.<sup>1</sup> Care plans need to acknowledge the inclusion of the patient as a recipient of the plan throughout an intricate and collaboratively formulated long-term follow-up trajectory.<sup>1,2</sup>

Northern British Columbia has poorer cancer-related health outcomes in comparison to any other region in the Province of British Columbia.<sup>1</sup> Challenges faced by male cancer patients and health service providers in rural and northern areas are very different from those that are faced in urban areas.<sup>3</sup> Treatments of cancers are complex and multi-faceted. Models such as shared care can become instrumental in providing well-coordinated survivorship care to the growing population of cancer survivors; particularly men.<sup>4</sup>

## Research Objectives

The present study has the following objectives: a) to examine the type of cancer care programs that may have focused on men with cancer in northern British Columbia (BC); and b) to identify challenges in care experienced by men with cancer during their transition from in-hospital care back to their home communities.

## Methods

### *Phase I: Literature Review*

A background literature review for this study was conducted in February 2014 using PICO categorization, where *P*=rural and northern cancer survivor(s), *I*=shared-care, survivorship plan, *C*=non-shared care patient plan, *O*=optimized, focused, and integrated patient care, enhanced health outcomes. The databases selected include MEDLINE (Ovid), CINAHL, and Cochrane. In MEDLINE (Ovid), the following MeSH keywords were catalogued: “cancer” OR “oncology” (494349) AND “shared care” (222). Of the resultant 9 findings, 6 studies were found to meet inclusion criteria. In CINAHL, the following MeSH keywords were searched in all-text: “oncologic care” OR “cancer care facilities” (all subject headings – 7392) AND

“survivorship care” (all subject headings – 3294). Of the resultant 13 findings, 3 were found to be relevant to shared care initiatives. Through Cochrane database searches, combining “shared cancer care” (keyword – 135) AND “survivor” (title – 238), 12 findings resulted, of which, 2 met inclusion criteria.

### *Phase II: Focus Group Methodology*

The focus group study was approved by the Research Ethics Board (REB) of both the University of Northern British Columbia (UNBC) and the Northern Health Authority (NHA).

A purposeful sample of health care providers was recruited to participate in a focus group held on February 20, 2014 at the University Hospital of Northern BC (UHNBC). A qualitative descriptive approach was used. Ethics approval to conduct the focus group was obtained through the UNBC Research Ethics Board (REB). Participants in the focus group were primary care physicians (PCPs), oncologists (*n*=8), and a convenience sample of male cancer patients (*n*=6) who have underlying obesity and Metabolic Syndrome (MetS).

The eight health care professionals (*n*=8) expressed interest in the focus group, as they have been working on other survivorship/shared care programs. Three general practitioners (GP), four general practitioner oncologists (GP-O), and one radiation oncologist (RO) participated in the focus group along with six men with cancer (*n*=6).

### *Data Collection*

The health care providers were asked to review and sign an informed consent form before participating in the focus group. A trained facilitator assisted in the conduct of the focus group in the multi-purpose room of the Regional Cancer Care Clinic at the University Hospital of Northern British Columbia (UHNBC). Two of the eight health care providers participated in the focus group using the telehealth communication system. The semi-structured focus group lasted approximately 2 hours, and all participants were asked to describe their previous experiences and local knowledge with shared care and/or survivorship care plans, as well as their ideas about what a shared care, cancer survivorship care plan would look like. The focus group started with the following semi-structured questions:

(1) What are the types of cancer survivorship and/or shared care initiatives that are already taking place in northern

B.C. that could be used to support or facilitate care plans, particularly in men;

(2) What could care plans look like for male cancer patients transitioning back to their northern BC home communities; and

(3) What would be needed in order to move this initiative forward?

### Analysis

The focus group proceedings were audiotaped and transcribed verbatim. The transcript of focus group data was analyzed by hand, carefully read by the facilitator and student assistant to identify meaningful themes in relation to the research objectives. Using a content thematic analysis,<sup>5</sup> the transcript themes were compared to one another to identify meaningful units. The themes and sub-themes were then refined through a process of triangulation.<sup>5</sup> The themes were compared to the literature review findings and further refined when the initial findings were sent back to the participants via email for validation.

### Findings

#### Phase I: Literature Review

The literature review highlighted that cancer care in northern and rural regions has generally not extended beyond surveillance for disease recurrence or occasional use of specialized services.<sup>4</sup> Comprehensive plans of follow-up, such as through electronic health record systems, that include monitoring for late effects and optimizing the use of specialized services have become developed and implemented only within the last decade.<sup>6</sup> Treatments of cancers are complex, multi-faceted, and can involve primary care physicians (PCPs), radiation oncologists, surgeons, and internal medicine specialists. The shared care model provides continuity of care for the cancer survivor while allowing the treating oncologist to focus primarily on patients undergoing active treatment.<sup>4</sup> The treating oncologist(s) remains involved and informed but is not burdened with the potential myriad of survivorship needs that can overwhelm a busy clinical practice.

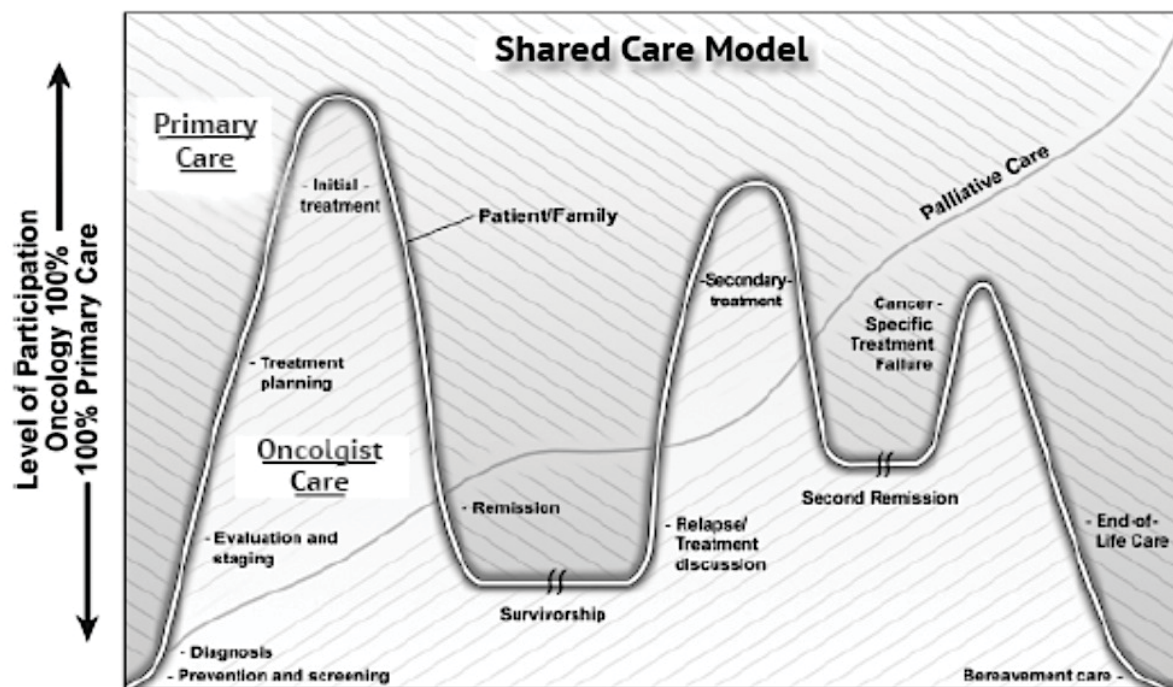


Figure 1. A general shared care model depicted across time, representing varying levels of participation of the oncologist and primary care provider, according to patient circumstance. Adapted from “A Model for the Shared Care of Elderly Patients with Cancer” by Cohen (2009).<sup>7</sup>

A shared care model can optimize the contributions and expertise of each discipline as they vary over time, promoting their most effective and seamless interaction throughout a patient's cancer journey. As illustrated in Figure 1, health care provider decisions need to be continually revisited on the basis of suitability in relation to continued cancer follow-up care and/or treatment.<sup>7</sup> These processes should be achieved through the shared interactions between PCPs, oncologists, patients, and their families.<sup>7</sup> Evaluations of the ways health care teams work together and the impact of these strategies upon patient/provider access to cancer care can assist to refine team collaboration and patient support.

### **Phase II: Focus group**

The focus group highlighted similar themes to those revealed in the literature review. In northern B.C. there has been initial information technology (IT) developments designed to: (a) improve access to patient records for health care providers to follow cancer survivors in primary care; and (b) to improve access to care for patients who have survived cancer and

returned to their community. In comparison to Vancouver, B.C.'s model where the ratio of 20 radiation oncologists to one GP-O exists, northern B.C.'s rural settings do not have a designated oncologist. The areas of northern B.C., outside of more urbanized Prince George, have structures that support innovations in primary health care that can be built upon to provide further support for shared care between specialists, GP-Os and GPs. This platform allows health care providers to collaborate, increase communication and share care of the patient. The platform can support health care providers to work, support, and learn from one another.

However, this innovation/platform is still in its development stages and needs to grow. The platform for shared care will need to be evaluated and modified. The cancer care team and cancer patients who participated in the focus group agreed that this process, in creating a platform allowing for shared care, would take time. The platform's evaluation needs to consider how increased access to patient records could affect: (a) confidence-levels amongst specialists who transfer care

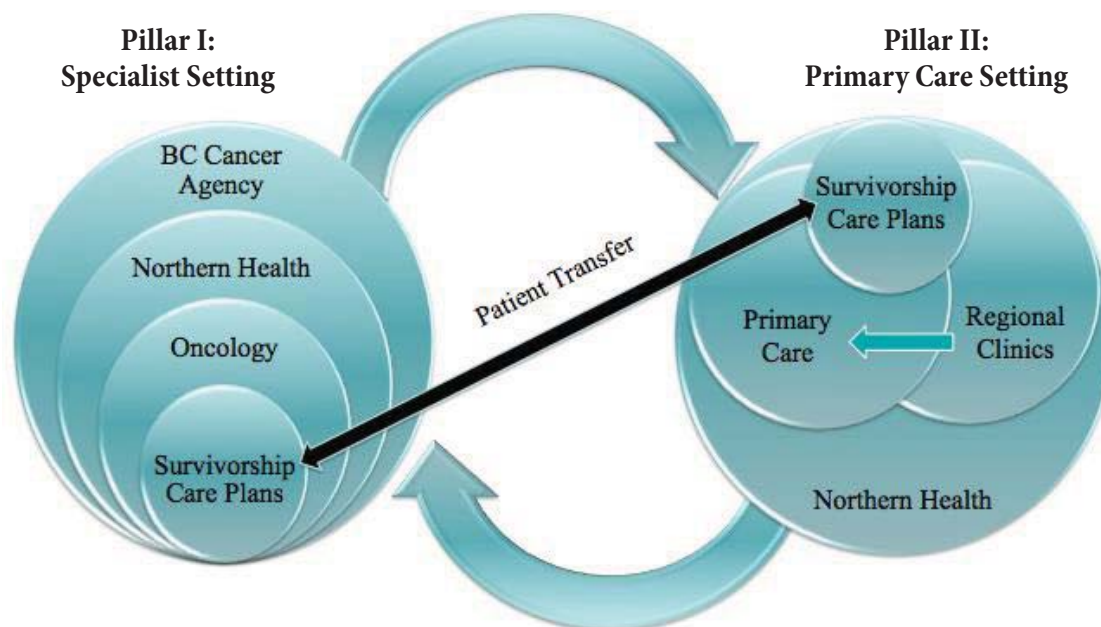


Figure 2. An outline of feedback loops within shared care evaluation amongst health care professionals and their respective system organizations that can assist to ensure effective evidence-based practice and knowledge translation. Survivorship care plans can act as mechanisms to ensure effective patient transfer. In northern B.C., patient navigation within the primary care setting is often facilitated by GP-Os, as patients are transitioned from clinics to primary care.



to GPs; (b) capacity building at the primary care level; (c) the privacy and confidentiality of patient records; and (d) workload for those involved.

Within Northern Health, cancer patient system navigation is often facilitated by GP-Os, beginning within regional clinics and then transitioning to primary care (Pillar II, Figure 2). Once the platform is modified to include evaluative feedback loops (Figure 2), it can be assessed to identify success factors and shortcomings, if required. The platform can continue to be modified over time based on feedback; eventually being incorporated in other regions across B.C., and Canada. Next steps would involve evaluating the platform in regions, comparing the process and identifying what works and why. Other potential opportunities would include using this shared care platform to increase communication amongst health care providers treating patients with other chronic conditions such as diabetes or the Metabolic Syndrome (MetS). Barriers that have been already identified have to do with defining responsibilities of those involved in shared cancer care strategies, as well as funding and deadlines related to funding that do not align with the in-depth process of evaluation needed for shared care platform implementation.<sup>4,7</sup>

### Discussion

Parallel analysis of *Phase I (Literature Review)* and *Phase II (Focus Group)* findings revealed three major themes: (1) patient perception and experiences on shared cancer care; (2) relationships amongst health care professionals; and (3) shared care strategies facilitating continuity within the health care system. (Figure 3) Within these three major themes, the following subthemes were identified: *innovation, collaboration, support, confidence, integrated health, access, and evaluation*. Subtheme terms are italicized within each major theme heading.

### The Patient Perception on Shared Care

Although studies generally do not provide sufficient information to draw conclusions regarding service utilization, shared care patients are significantly more likely to rate their care as very good to excellent, while undergoing shared-care service approaches.<sup>8</sup> Patients with cancer may feel initially uncertain about what is going to happen when they are referred to a hospital and may experience psychological morbidity and dissatisfaction with the provision of information and care.<sup>9</sup> Drummond<sup>10</sup> suggests that any gaps in patient perception of service *access* and mean patient satisfaction scores reflect patients' lack of initial *confidence* in primary care when they are



Figure 3. The relationships amongst the patient to health professionals to the health care system are integral themes within the overall model of shared care strategies. The relation each has to the other can be best represented through a pyramid paradigm, where each component supports overall structure.

accustomed to receiving regular specialist care. An *integrated* shared care program has positive effects on patient *evaluation* of attitudes toward the health care system, health professional *collaboration*, feelings of isolation, and contact with the GP.<sup>11</sup> Better *support* of patient attitudes and perceptions can assist to maximize patient compliance and treatment outcomes.

In our focus group study, men with cancer (patients) emphasized the importance of several aspects in their contact with survivorship healthcare services: physician's technical competence, communication skills, family care, continuity of patient care, and financial circumstances.<sup>11</sup> Most patients with cancer are treated as outpatients, and may therefore feel that they are left independent at crucial moments, which is why young men as patients particularly benefit from shared care programs.<sup>11</sup> At such times, these men often consult their GP for further advice when presented with treatment options, information, and repetition of information.<sup>11</sup> These situations occur frequently and may be remedied by sharing the care between GPs, GP-Os, and oncologists. The shared care program evaluated by Nielson and colleagues<sup>11</sup> had a significantly positive effect on patients' outlooks upon *collaboration/cooperation*, *support*, feelings of not being left in silo, and their attitudes towards and reported contact with their GP.

### Relationships amongst Health Professionals

Some roles and responsibilities of the oncologist include diagnosis and staging of cancer, cancer therapy, keeping the patient's PCP(s) informed, transitioning the patient to primary care at an appropriate time, frequent care plan *evaluation*, and offering guidance in long-term survivorship care.<sup>6</sup> The PCP is expected to ensure the emotional and physical needs of the survivor are addressed, assume responsibility for aspects of care for the chronic disease that are feasible in the primary care setting, consult/*collaborate* with oncologist when there are issues of uncertainty, assist in regular patient care plan *evaluation*, and refer the patient for problems and/or periodic *evaluations*.<sup>6</sup> Some points along the patient's journey when communication and *collaboration* should occur between the oncologist and the PCP include (a) cancer diagnosis and planned therapeutic approach; (b) formulation of the patient's survivorship care plan: a summary of cancer and cancer therapy, potential late effects, up-to-date recommendations for monitoring of recurrence and late effects; and (c) continued

update with changes in surveillance recommendations and new information regarding late effects. It is important for both PCPs (GPs and GP-Os) and medical oncologists/radiation oncologists to liaise with one another in *confidence*. Such processes could be achieved through the *innovative* mechanisms of a cancer survivorship care plans *accessed* electronically and individualized (tailored) for each patient.

Through *evaluating* the shared-care model, key patient outcomes often investigated include mortality, morbidity, and health-related quality of life.<sup>1</sup> Owusu and Studenski<sup>12</sup> conclude that many patients would be willing to have their GPs share their cancer follow-up with the caveat that they have robust *support* from secondary/tertiary care as well as have previously received extra specialty training. Another barrier to the implementation of shared-care is that many cancer patients are treated for one year and then are closely followed by the oncologist for another one to two years, instead of being transferred directly to primary care following active treatment.<sup>1</sup> Additionally, radiation and/or medical oncologists will often follow cancer existing at rare tumour sites, since clear protocol practice guidelines do not exist (BCCA personal communication, April 8, 2014). A primary example for this situation is within the field of pediatric oncology, where it is often assumed that the GP would be uncomfortable in providing sole follow-up (BCCA personal communication, April 8, 2014).

During time periods when the long-term survival of the patient is still in question, medical oncologists, with their internal medicine backgrounds, may manage the patient's comorbid conditions.<sup>6</sup> Radiation oncologists, who generally do not have internal medicine backgrounds, may also follow patients for prolonged periods of time, such as for head-and-neck cancers, for up to 10 years (BCCA personal communication, April 8, 2014). By reducing the number of visits to different clinicians during a time period when the patient is often susceptible to infection or is feeling the ill effects of their cancer or chemotherapy, the patient's care can be streamlined. Though as the patient disconnects from their PCP, and is managed solely by the oncologist, care may be sub-optimal as only one specialty is involved.

The unique role of GP-Os in Northern Health poses a demand for reassessment/*re-evaluation* of the roles and responsibilities

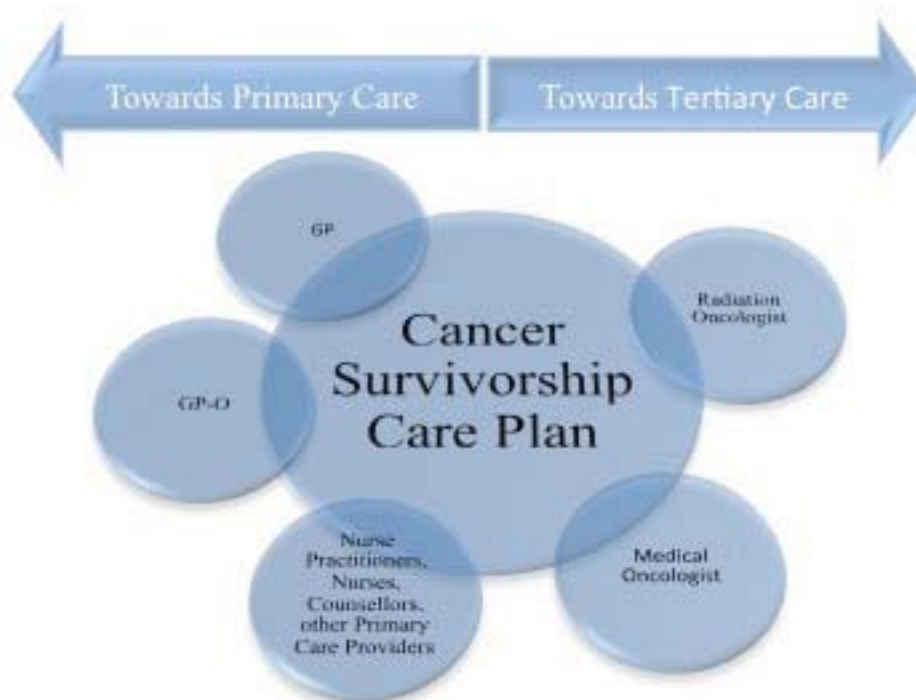


Figure 4. Cancer Survivorship Care Plans serving as an interface for collaboration amongst health care professionals involved in the continuity of care between primary and tertiary services.

GPs and specialists assume within health practice. As illustrated in Figure 4, cancer survivorship care planning amongst health professionals must *integrate* and involve the contributions of a number of individuals. Some argue that there remains a wide gap between the information that PCPs need/request, and the information provided to them by oncologists.<sup>11</sup> Proponents advocate that increasing capacity in primary care could create further demands for specialist services; more cases and complications could accumulate as quality of care improves.<sup>8</sup> In Northern Health (NHA), navigator roles amongst health care professionals are in place, but these roles need to be formalized through facilitated communication while ensuring that the roles and communication processes are consistent throughout regions in northern B.C (NHA personal communication, April 16, 2014).

### Shared Care Strategies Facilitating Continuity

A shared-care approach is inferred through optimized cancer survivorship care including seven components: (1) increased awareness of the needs of cancer survivors, and establishing cancer survivorship as a distinct phase in the delivery of cancer care; (2) compiling a comprehensive survivorship care

summary/plan; (3) developed quality of survivorship care *evaluations* to monitor care; (4) interdisciplinary/*integrated* survivorship care; (5) promoting refinement of existing cancer control plans; (6) coordinated educational opportunities to health care providers to address a diversity of cancer survivorship issues; and (7) ensuring cancer survivors have *access* to adequate and affordable follow-up care.

Cancer survivorship entails the cancer continuum beginning with initial diagnosis through the remainder of one's life.<sup>13</sup> More specifically, cancer care is focused directly after active cancer treatment and comprehensively extends over the physical, mental, and social aspects of the cancer experience. Broadly concentrated on surveillance for disease recurrence, other significant health problems may become more apparent later in the course of one's cancer trajectory.

As intermittent communication between primary care physicians and cancer specialists may take place, coordination of follow-up care often varies.<sup>13</sup> The shared care model amplifies the use of existing resources, thus may enable better implementation. A care manager can also be

proposed as a potential refinement of the shared care model -- to serve as an intermediary between the oncologist and primary care physician.

Shared cancer care systems/plans (SCPs) frequently include pre-specified clinical protocols, referral guidelines, continuing education of participating clinicians, specifically designed information exchange systems and ongoing audit and *evaluation* of services delivered.<sup>8</sup> Hoskins et al.<sup>14</sup> described a purpose of shared care intervention services being able to relieve pressure on specialist services and to contain costs. Drawing from economic outcomes, patient direct costs are also lower when comparing shared care with hospital outpatient care, primarily due to decreased travel/relocation costs.<sup>8</sup>

Members of a multi-disciplinary team can bring their own expertise to provide a patient-centered approach. A lack of certainty over roles and responsibilities, a paucity of formal training in oncology for PCPs that may result in a reluctance to participate actively in the care of oncology patients, and lack of understanding of the culture of primary care on the part of oncologist may pose potential barriers to shared care on each side of the primary-oncology care interface. As cancer survivors are increasingly demanding comprehensive coordinated care, organizations such as the World Health Organization (WHO) identify *integration* of health care services through practitioner *collaborations* as being a key step in achieving this goal.<sup>11</sup>

## Conclusion

Three concepts governed by shared care strategies support the feasibility of such care model in northern British Columbia: patient-focused quality of care, collaborative health care professional relationships, and system capacity building through shared care strategies facilitating continuity of care. Initiatives to improve the quality of care provided to cancer survivors have become a priority of survivorship advocates and policy makers.<sup>11</sup> The increasing prevalence of cancer, growing complexity of cancer therapies, and unique aspects

of cancer survivorship are factors that justify the benefits of a health care team caring for people living with cancer.<sup>11</sup> Shared care treatment summaries and survivorship care plans can empower the cancer survivor as well as GPs/GP-Os and specialists through collaboration with one another.

Knowledge translation (KT) principles through provision of cancer-specific information may be facilitated through information technology (IT) mediums for effective health service delivery. Members of a multi-disciplinary team which include health professional and IT personnel may bring their own expertise to provide a patient-centered approach. Representative evaluation that effectively outlines merits of shared care strategies can reduce barriers to shared care platforms. Implementing change can occur through optimizing synergy amongst health care professionals, as well as patient cancer survivorship care in concert to enhancing health care system integrity.

Finally, there are implications of an integrated shared care model (program) for obese cancer patients. There is evidence that obese cancer survivors and their primary care physicians are receptive to the concept and benefits of shared survivorship care plans (SCPs). Many of the previous published studies on the content and delivery process of SCPs were derived from focus groups (similar to the focus group methodology in our current study), interviews, and surveys.<sup>15</sup> While the majority of these studies were observational and relied on survivors' self-report (as in focus groups), the themes that emerged from such focus groups provided useful information from both the health care provider and patient perspectives. Physician-delivered SCPs seem ideal within an integrated shared care model. Feasibility, lack of time and financial resources were identified, however, as significant barriers to successful implementation of SCPs. Future studies should evaluate the short-term and long-term effectiveness of SCPs using not just observational cross-sectional study designs, but employing randomized controlled trials (RCTs).



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